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Delivering palliative care the CanSupport way

INTRODUCTION

In India, more than one million people are diagnosed with cancer annually. Almost 80% are incurable. The country is estimated to have an equal number of patients with other incurable diseases, such as HIV/AIDS, and with progressive neurological, cardiac and respiratory disorders. The case for instituting palliative care services nationwide could not be more pressing.

The CanSupport home care program was initiated in 1997 by Harmala Gupta, a cancer survivor. She approached the then Director of AIIMS, Dr. P.K. Dave. A pilot project began with 6 patients with terminal cancer being referred to CanSupport's free of charge home-based palliative care service. These patients lived within a 25 km radius of AIIMS. After 6 months, patients began to be referred on a regular basis to CanSupport.

Today, CanSupport has 23 home care teams located in different parts of the capital city and the National Capital Region (NCR). They look after more than 1300 cancer patients, in their homes, at any one time. It continues to be a free service.

PATIENT CARE AT HOME

Patients with advanced cancer suffer from both physical symptoms[1] and psychosocial problems, which adversely affect their quality of life. Palliative care delivery at home by multidisciplinary teams has been shown to improve the quality of life of these patients and their families.[2,3]

CanSupport provides such care to patients with advanced cancers and their families through its multidisciplinary teams, each of which consists of a doctor, a nurse, and a counselor. All team members are provided with training in palliative care on joining the organization.

Referrals come from a number of hospitals that treat cancer in the city, as well as from past beneficiaries and through the helpline. Patients reside all over Delhi and the NCR. There are 10 strategically situated field centers; each of which has 1-3 teams. Team members travel together in a hired vehicle, covering a radius of 25 km from these field centers.

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Each team cares for 50-60 patients at any given time. Their patients are prioritized as high, medium or low according to the urgency of their problems, which may be physical or psycho social.

Patient care is individualized and meets each patient's/family's specific needs. Management of care is divided among team members. The nurses are the coordinators and decide which patients are to be visited in consultation with the doctor and counselor. Apart from nursing needs, they also educate caregivers on nutrition, oral/wound/ostomy care and prevention of bedsores. Procedures such as nasogastric tube insertions, urinary catheterizations and short infusions are done at home.

Efforts are made to explain all aspects of the patient's condition and the plan of care to patients and/or their caregivers-symptoms, likely improvements, medicines and their side effects, and what to expect as the disease progresses. Family members are also prepared as the end draws near and helped to keep the patient comfortable. This takes away their fear about the suffering their loved one will have to endure at the end-of-life and removes doubts about their ability to manage.

Psychosocial support is provided mainly by counselors who are trained to listen and address patients and caregivers emotional, social, financial and spiritual concerns. They help them come to terms with the prognosis of the disease, advise patients on practical matters and assist patients to mend relationships with parents, siblings or children. Since the majority of our patients are underprivileged, counselors also assess whether they are eligible for rehabilitation support from CanSupport or government agencies. Counselors provide bereavement support to families' up to 6 months after the death of a patient.

Our teams work from 9 a.m. to 5 p.m., Monday to Friday. Outside these days and hours advice is available over the phone, 24 × 7, from both doctors and nurses. The teams also try to network, where possible, with local family doctors for out-of-hours care.

With the support of CanSupport's homecare teams, patients and their families are able to come to terms with the reality facing them and manage most of the problems associated with a terminal illness within the comfort of their homes.

EDUCATION, TRAINING AND COLLABORATIVE RESEARCH

In order to maintain a high standard of care, CanSupport has an ongoing education and training program for home care team members. Training workshops are also conducted

for other health professionals on request. We try to ensure that our training programs are evidence based and culturally appropriate. Programs that are conducted on a regular basis are as follows:

1. Training for new recruits: A 1-month certificate course in Palliative Medicine for doctors and in Palliative Nursing for nurses is conducted once or twice a year. There is also a 3 months counseling course for counselors. All new recruits are required to go through training in their respective fields on joining. The training is both theoretical and practical.
2. Training of existing staff: Fortnightly trainings sessions which maybe in-house or external trainings. In-house trainings consist of role plays, presentations, discussion of case scenarios, etc., and everyone is expected to participate. For external trainings, faculty members from outside CanSupport are invited.
3. Training of Health Care Professionals: A number of introductory Palliative Care Workshops are conducted in medical colleges, nursing schools, and hospitals every year.
4. Annual Foundation Course in Palliative Care, of 3 days duration, for doctors, nurses and social workers/counselors is conducted yearly in partnership with AIIMS. This year will be the 14th of this course.
5. Outside Projects: We are currently training doctors, nurses and social workers in Punjab, Srinagar and Bikaner to start and/or strengthen their Palliative Care activities.

SUMMING UP AND LOOKING AHEAD

CanSupport's steady growth undoubtedly owes a great deal to the caliber of its home care team members, volunteers and staff. Their high standards of professionalism and team spirit are an inspiration. This is not to say that there have not been challenges. It took CanSupport almost 5 years to obtain a license for oral morphine and to gain acceptance from law makers and medical practitioners, among others, for its path-breaking work. Raising funds for a service which is rapidly expanding in response to growing demand is also not easy.

There was also the issue of CanSupport transforming itself from a volunteer-led organization to one managed by professionals. Accordingly, in 2007 CanSupport drew up a Five Year Plan and identified strategic goals to be met by 2012. One of these was to appoint a professionally qualified and salaried CEO to replace the founder Harmala Gupta. This was accomplished in April 2012.

At the end of the Five Year Plan period, CanSupport decided to look ahead and work on a road map for the next 10 years: 2012-22. This exercise threw up the following challenges for CanSupport as it continues its growth momentum:

1. Maintaining the caring culture which currently manifests itself in the high quality of its services and in the satisfaction of those who use them.
2. Scaling up its current operations to cover a wider geographical area and a larger number of patients without affecting quality of delivery.
3. Sustaining services as the concurrent need for more resources grows: Financial, technical, trained manpower, etc.

Going forward, the answers will lie in Can Support's ability to:

- Transmit its culture through skillful training, ongoing monitoring and leadership.
- Build a Corpus Fund to neutralize the effect of financial fluctuations.
- Restrict its directly managed operations to Delhi and the NCR and instead expand its national footprint through training and research activities.

To conclude, CanSupport is today on a very successful growth path in large measure because of its willingness and ability to move forward in a planned manner. It is a value-driven organization that prides itself on its transparency and integrity in its dealings with all stakeholders. The ethos is democratic and nurturing. This has helped build a sense of collective ownership and responsibility which reflects itself in the high ratings given by users to CanSupport services. We believe that CanSupport has perfected a model of palliative care delivery which is best suited to conditions on the ground and which has the potential of revolutionizing the quality of medical care for people with life limiting diseases in India.

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