

DIFFERENT WAYS TO INITIATE COMMUNITY SUPPORT –in palliative care

Prof (Maj) Pramod Patra.

MD. Anaesthesiology & Critical Care.(DELHI UNIVERSITY)

Senior Consultant & Head

Department of Anaesthesiology , HCGPanda Cancer Hosp, Cuttack

FCCSCC Critical Care

PDCC in Essentials of Palliative care

Fellowship ECHOCARDIOGRAPHY.

Owner of Steel City Hospital, Kalinganagar.

Chairman Cum Settler of BRUNDABAN KHINAMANI CHARITABLE TRUST

When
DESPAIR
MEETS
HOPE.....



PLA

Pramod

... PALLIATION is the ANSWER

WHO definition of Palliative Care

“an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.”

THE GOAL OF PALLIATIVE CARE

- To improve the **quality** of life (of both patients and families) –**adding LIFE to YEARS**
- by responding to **pain** and other **distressing physical** symptoms.

And to provide

- nursing care
- psycho-social
- and spiritual support.

This is why it is best administered by an **interdisciplinary,**
multi-dimensional team,

comprising doctors, nurses, counselors, social workers, and volunteers.

WHO guidelines for Palliative care includes:

- • providing relief from pain and other symptoms;
- • regarding **dying as a normal** process;
- • neither hasten or postpone death;
- • integrating psychological and spiritual aspects
- • help to live an **active life until death**
- • Ensuring their **quality of living**;
- • **help family to cope** with patients illness.
- • And extending support during bereavement;

Models and Agents of Palliative care

- ▶ **Different models of palliative care exists,** (which offer care services through varied agents) despite :-
 - ▶ absence of national policy on palliative care,
 - ▶ inadequate recognition of the specialty,
 - ▶ lack of required infrastructure and trained specialist
- ▶ **These models can be classified as:**
 - ▶ Pain and symptom management centres
 - ▶ Home care units
 - ▶ Day care Centres
 - ▶ Hospice care
 - ▶ **Community based model**



Mr Jan Stjernsward (Chief of Cancer – WHO)

- ▶ **“The same attention we give those that enter life, the newborn, we should give those that leave life, the elderly and terminally ill”**

Gandhian spirit :

“for the people, by the people, with the people”.

Levels of community participation

community engagement is needed at varied levels,

➤ 1. Manipulative Participation

Pretence, with nominated representatives from the community having no legitimacy or power

➤ 2. Passive Participation

Unilateral announcements without consulting the local community

➤ 3. Participation by Consultation

External agents play the key role by defining problems and information gathering processes and thereby control analysis, dictate direction .



Contd....levels

4. Participation for Material Incentives

People participate by contributing resources (labor) in return for material incentives

5. Functional Participation

External agencies encourage participation by local community to meet predetermined objectives

6. Interactive Participation

People participate (as a right) in joint analysis, development of action plans and formation or strengthening of local institutions

7. Self-Mobilization

People take initiatives independently of external institutions to change systems

Community Engagement in Palliative Care-

a core approach to improve population health. health for all is health with all, and that for it to be **sustainable**, it must be **owned** by the community

➤ Community engagement as defined by WHO:-

“a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, making decisions about factors that affect their lives, formulating and implementing policies, planning, developing and delivering services and taking action to active change.”

➤ Purpose of Community engagement in end-of-life care

It is an umbrella term.

It's a process which enables communities and organizations to work together :-

- to understand,
- to build capacity and
- to address issues
- and to improve their experience of end-of-life and bereavement.

Community Participation- Different Terms One Goal

Community participation is described as :-

- a social process in which **groups with shared needs** living in **a 'certain geographical area'** actively **identify** needs, make **decisions**, and set up mechanisms to **achieve solutions**.

Other terms like-

- community mobilization
- community-led
- community-focused

are also being used imprecisely by palliative care programs

Community empowerment

- **The cultural and socio-economic factors are equally or more important** to what kind of death we face, than the purely medical.
- There is an **overemphasis on the medical approach**
- and only by **empowering the community** can this be balanced.

- **local communities can be empowered**
 - **to identify** the chronically ill and the terminally ill, regardless of disease or cause, and
 - **to support them and their families** with self-sustainable community led services despite limited economic resources and without any outside economic support.
 - **to take responsibility** for the care of its own chronically and terminally ill.

Potential Of Community Involvement

- Only realistic model for achieving significant coverage of care.
- knitting up The social web is probably a key factor in the success
- Meaningful palliative care requires a combination of
 - -socio-economic
 - -cultural, and
 - -medical solutions

active involvement of the community in addressing all three factors.

Potential of community care:

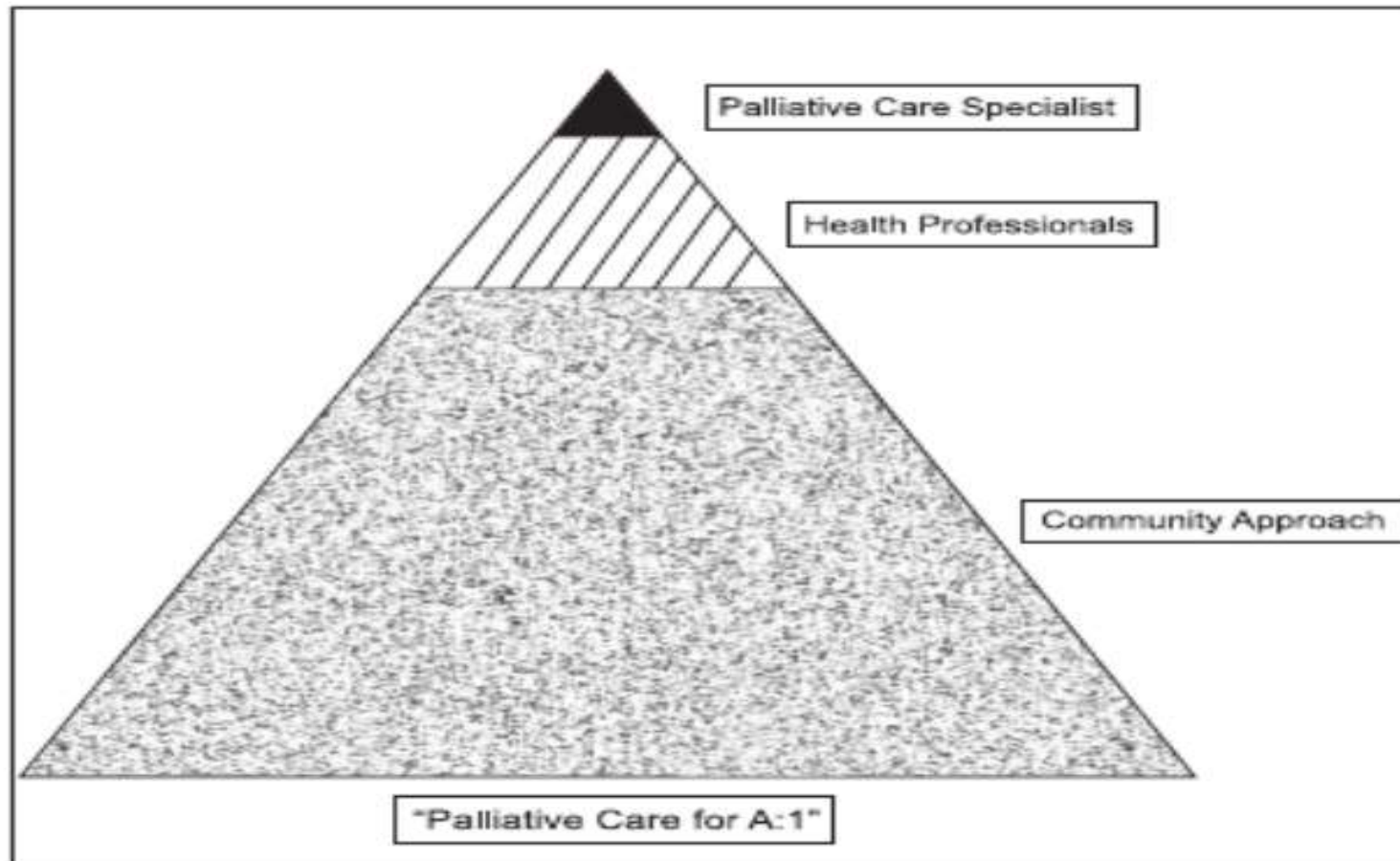


Figure 1: Dissemination of Coverage

The 4 principal requirements for home care:

- Social support
- Psycho-spiritual support.
- Nursing care .
- And medical clinical management.

The **community approach** can address at least the first three.

Scope Of The Community engagement:

- Achieving proper nutrition
- Relieving social isolation
- Alleviating poverty
- Establishing contacts
- Assuring family support
- And maintaining basic hygiene are **priorities in social support.**
- Information, referrals, and needed transport by volunteer privately owned cars.
- Helping with unfinished business



Scope.....contd

- Recognising a depression and informing the health professionals
- To share a moment, a look, a silent appreciation, a touch, to listen, and to show empathy.
- Supporting and empowering the family members .
- Last but not the least- nursing care
 - such as wound care
 - cleaning out of maggots,
 - doing bed sore prophylaxis,
 - promoting and maintaining good hygiene
 - and nutrition,
 - supervising the taking of prescribed medications

Drawbacks In Implementation

Three of the major impediments for implementing existing knowledge are-

- Weak human resources.
- Lack of institutional infrastructure.
- And lack of financing.

These problems have to be solved before knowledge can turn into action and improve health systems.

What are the limitations?

The world is the limit.

- ▶ May not get needed support from the medical profession.
(**Bcoz of low cost affair- will hamper business of clinical care givers in big institutes**)
- ▶ Terminal care and death can easily be commercialised in india.
Few vested interests may jump to earn profits out of the services.
- ▶ Criticism from the medical fraternity
- ▶ Other obstacles like-
 - ▶ Population density, poverty, geographical diversity, restrictive policies regarding opioid prescription, workforce development at base level,
 - ▶ Limited national palliative care policy
 - ▶ Lack of institutional interest in palliative care.

Advantages of community participation

- Responsibility and ownership (by the people for their own people)
- Ethical standards of equity- (All covered irrespective of socio-financial status.)
- Alternative to costly and unaffordable care-(the present over-medicalised, over-specialised, institutionalized care.)
- Financial self-sustainability – (money being raised by the people/society themselves.)
- Empowered volunteers and laymen – (social support, psychosocial support, nursing care and even medical clinical management)
- Alternative source of encouragement to the moral decline.
- More acceptable to the patients-(Own and known people are more acceptable in times of distress and despair.)

How To Initiate Community Support:

1. **Identify** people in the area : **for different levels of community participation**

- ▶ **Philanthropists, Service Inclined, Sympathetic, Financially Stable**
- ▶ **Small Miniature Organisation Around The Area**
- ▶ **Sports Clubs, Cultural Clubs, Bhagabat Tungi, Kitty Groups, Self Help Groups**
- ▶ **Identify Educational Institutes - Schools, Colleges.**
- ▶ **Medical Institutes, Nursing Homes, Old Age Homes, Orphanages,**

2. **Approach**- these people by setting examples

3. **Involve** – them with active participation- allot small tasks

4. **Observe** – their interest and segregate interested from the uninterested

5. **Divide tasks**- active physical care, fund raising activity, transport services, clinical care, last rites, family support.

How To InitiateContd...

➤ Maintenance of their interest-

- small moral boosting functions like get-togethers, feasts, picnics, kirtans involving the patients and the volunteers

➤ Research and data keeping-

- involve the educated, smart people in the neighbourhood for maintaining records, data.

➤ Fund raising-

- door to door collections of small donations in cash or kind- blankets, food raw materials rice, vegetables, medicines, clothes
- Small competitions and lotteries within communities
- Approach Govt and other bigger philanthropic institutes for donations
- Organise meetings with potential donors –and impress them with ideas of celebrating Bdays, marriage anniversaries differently

➤ Gain confidence and trust of the community

- Truthfulness and transparency in dealings

➤ Showcase what you do-

- advertise, announce events in public, invite well known guests for programmes

Philanthropic Mind Set In India

- **High social dependency-people** from the indian subcontinent.
 - This leads to expectation of empathy as well as being empathetic towards others.”
 - It is ingrained in our culture and tradition
- The government in india has **mandated corporations-**
 - To spend 2 per cent on corporate social responsibility (**CSR**).
- **90 percent** of indian population have a **sympathetic mindset** towards fellow beings
- **79%** amongst women
- **64%** amongst men feel empathetic towards society and fellow beings
- **But only 1 to 2 percent get to actually involve themselves.** Rest of them lack opportunity, time, seek cajoling, lack directions, lack ideas etc
- **How to identify such the mind set:-**
 - Relationship with people in families, maids, drivers etc
 - Helping community members migrate to greener pastures for a better living
 - Donating to religious institutes-temple trusts, waft boards, madrasas, churches etc

- Do Something For Each Others 🙄🌹

