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Awareness building and improving participation of local communities in palliative care

Abstract

Many people are experiencing serious health-related suffering that would benefit from palliative care. However, this service is inaccessible or underdeveloped in many parts of the world. One of the main starting points for introducing or developing palliative care services is improving awareness and participation in palliative care in the community. A group of clinicians from diverse backgrounds discussed how to implement this and this paper is a culmination of ideas arising from these conversations. For awareness building, social media campaigns, awareness at food festivals, national palliative care day programs, sharing stories and testimonials to stimulate conversations regarding palliative care and a “human library” project were described. For improving community participation, community volunteer development programs, the “adopt a grandma” initiative, medical student palliative care project, workshops and training for non-communicable diseases and community nursing cross-specialty collaborations are suggested. It is hoped that these proposals will stimulate further ideas and support the implementation of palliative care in different settings.

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Introduction

The provision of palliative care is a global health issue. The Lancet Commission Report on Palliative Care and Pain Relief in 2017 found that almost half of those who die each year experience serious health-related suffering that may benefit from palliative care, of which 80% are from low- and middle-income countries [1]. Thus, a call for the inclusion of palliative care into health plans as part of universal health coverage was made. An online survey from 2017 found that palliative care at the highest level of provision was only available for 14% of the world population, and was found mainly in European countries. Much work needs to be done to develop this service, particularly with a predicted 87% global increase in serious health-related suffering predicted by 2060 [2].

There are many areas to develop in terms of palliative care. A national palliative and end-of-life care policy is required to ensure palliative care remains prioritized, funded and supported by policymakers [3]. Before patients get access to or are referred to palliative care services, clinicians need to recognize those who would benefit from these services. This requires an understanding of the trajectory of illness and acceptance from clinicians, patients and their families that not all conditions are curable [4]. After clinical guidelines are developed, there may be barriers to consistent implementation across healthcare settings, including hospitals, communities and hospices [5]. Palliative care approaches are holistic and require conversations with family, which should be adapted to different cultural settings [6]. In addition, further consideration is required to plan how to reach those in need of these services, as access may be challenging for those living in rural areas, especially in developing countries [7]. Finally, many developed services were affected by the COVID-19 pandemic, with much effort required to build back up towards the pre-pandemic capacity [8].

For many countries, the main starting point for the introduction or development of palliative care services is in the community, especially awareness raising on palliative care. In this paper, several initiatives or interventions are suggested to improve the awareness and participation of local communities in palliative care. The ideas stem from conversations and discussions on how to promote palliative care in different settings. The authors are clinicians who practice palliative care but have varying backgrounds in terms of specialties ranging from orthopaedics, anaesthetics, community medicine and geriatrics; and countries including India, Bangladesh, Iran, Thailand,

Myanmar and Brunei. These discussions occurred as part of a Fellowship in Palliative Care jointly organized by St Christopher's Hospice (London, United Kingdom) and the Institute of Palliative Medicine (Kerala, India). It is hoped that these proposals will stimulate further ideas and support the implementation of palliative care in different settings.

Awareness building on palliative care

The suggested approaches for awareness building on palliative care are as follows: social media campaigns, awareness at food festivals, national palliative care day program, sharing stories and testimonials to stimulate conversations regarding palliative care and a "human library" project.

Social media campaigns

As the topic of death and dying may be viewed as taboo in some communities, social media may be utilized to normalize these conversations. This may increase the willingness of people to openly share their personal experiences through online discussions, comments and anecdotes about illness, disease, hospitals, death and dying [9]. For this campaign, it is important to develop content and a social media calendar to ensure regular posts. Promotional materials and links to relevant virtual events are required to lead audiences to the planned online activities. Instagram and Facebook may be utilized to share infographics and videos while Instagram Live and YouTube may be used to host live talks online. Facebook is useful for group discussions to raise awareness and clear doubts. Facebook support groups can also be set up for specific conditions, assisting people undergoing rehabilitation, bereavement or grief. Social media may also be used to poll for public opinions. Fundraising or crowdfunding may be facilitated by linking those in need and those who wish to contribute through social media. Vocational rehabilitation assistance may also occur through LinkedIn to identify suitable jobs.

While social media is mainly online, people are still required to come up with content. Students from arts or media faculties may be involved in designs and slogans. Suitable people who initiate discussions and share stories of how they recover or overcome adversities may encourage participation from others. Bloggers and vloggers may be invited to visit palliative care services for posts. Public participation in activities, particularly involving celebrities, is effective for social media campaigns, as seen in the ice bucket challenge for motor neuron disease.

National palliative care day program

World Hospice and Palliative Care Day is observed on the second Saturday in October every year. An awareness campaign can be planned in conjunction with this event. There is a campaign toolkit available from the website, containing logos, themes and media releases that can be adapted for local use [10]. Social media platforms may also be used to amplify the messages.

In addition to people showing support through wearing theme colours or ribbons, having physical events and a coordinator is advisable. This can be in the form of public talks or open forums by cancer survivors or families about overcoming their challenges. Palliative care survivors or recipients of palliative care who are not imminently dying can share their stories to advocate for earlier referrals to palliative care and emphasize the importance of quality of life despite experiencing life-limiting illnesses. Exhibitions displaying creative products from palliative care survivors or differently-abled may be auctioned to raise palliative care funds. Other previous events held in commemoration included cricket matches, cycling, tree planting or life celebrations in cities and parks. Launching palliative care helplines, websites or applications on the day may help promote these services. Gala award nights may also be held for the recognition and appreciation of volunteers.

During World Hospice and Palliative Care Day, hospitals and primary health care centres may offer open clinics or free consultations to familiarize the community with palliative care. Mobile clinics may also be set up in villages at strategic locations, such as mosques and temples with assistance from non-governmental organizations and volunteers.

Food festivals

As the adage goes, the way to a person's heart is through their stomach. The local palliative care team may engage restaurant chains or hotels for partnerships. For example, an international food festival at a hotel, buffet Saturdays or happy hours with discounts or funds towards palliative care survivors and caregivers would help raise the profile of palliative care [11]. During the COVID-19 pandemic, many home chefs and young entrepreneurs were starting pop-up kitchens, cloud kitchen services and canteens. Their involvement in addition to conventional restaurants may be beneficial in inspiring other youths to get involved in palliative care initiatives. Collaborations with food delivery chains may work, such as providing discounted menus for palliative care survivors, caregivers or volunteers. Zomato also ran a "turning the tables" campaign for cancer awareness fund-

raising, where they contributed funds for each dine-in booking received [12].

In India, the langar ("free kitchen") lunch or dinner concept is a Sikh tradition to feed the hungry. This is usually organized using local funds or by religious groups on auspicious or martyrdom days. During the service, spiritual teachings and stories are shared, with volunteers doing the cooking, serving and cleaning as part of the spiritual process. This can be done at different premises other than religious places, such as hospices and caregiver rest houses. These events are also opportunities to recruit palliative care volunteers, raise funds as well as share palliative care information and pamphlets.

Sharing stories and testimonials to stimulate conversations regarding palliative care

Stories, testimonials and shared experiences can help stimulate conversations around difficult topics such as palliative care [13]. Patients and families should be encouraged to share, especially those who will benefit from emotional relief, improved autonomy and reduced social isolation through storytelling. Listening to their stories may also have a therapeutic value through offering a process of reflection and feelings of well-being and compassion. To support this, it is important to create independent, comfortable opportunities for people to share. This can be through feedback surveys (printed or online), coffee chat sessions (in-person or online), or peer group caregiver meetings. Another consideration is whether the person should be anonymized and obtain written permission to share the experiences, following local legal and ethical norms.

Among healthcare workers, the palliative care team may facilitate and organize storytelling workshops. Topics and scenarios related to palliative care in practice and how to deal with death and dying are beneficial. Health workers can attend to share their experiences to reduce burnout and stress, widen their knowledge and motivate their participation in palliative care practices. Palliative care survivors may also be invited as guests to share their stories, which improves awareness of how to support them with their palliative care needs.

"Human library" project for public and community awareness

This project has been piloted in a Bangladesh setting and was well-received by the community. Instead of books, humans are the resource material or an open book with life experiences. The resources come from several groups: palliative care patients such as cancer survivors, formal or informal caregivers, compassionate

volunteers active in the community, health care professionals (doctors, nurses, physiotherapists, occupational therapists, counsellors, psychotherapists, ward boys, ambulance drivers), spiritual leaders and students from local academic institutions.

The sessions are located in an open public space, usually a park on pre-specified dates (first weekend of alternate two months for two hours in the afternoon). There are six groups with two members each, providing one-to-one personal interactions with passersby for 30 minutes each. This is all voluntary and there is no payment required to access this service. However, there is a charity corner for those interested in contributing to individual needs-based donations. Conversely, people may be able to seek assistance from the community here. There are currently plans to expand this project to other localities, with community mapping to plan strategic places and identify local advocates or palliative care champions as resources.

Community participation in palliative care

The suggested approaches for improving community participation in palliative care are as follows: community volunteer development programs, the “adopt a grandma” initiative, medical student palliative care project, workshops and training for non-communicable diseases and community nursing cross-specialty collaborations.

Community volunteer development programs

For volunteer programs, there is much groundwork and planning needed to ensure sustainability. Active participation and mandatory training of palliative care support workers are required. For example, in India, there are Accredited Social Health Activists (ASHA) workers who are trained according to modules from the National Health Mission. Governing bodies such as Panchayati Raj Institutions provide bureaucratic roles and oversight to ensure accountability [14]. Village leaders, volunteers and non-governmental organizations work together on problem-finding and solving activities to foster shared responsibilities for community health and social wellness.

Students from health-related professions are potential sources of volunteers, with the institutions providing internship training and support. Monthly meetings are recommended to ensure ongoing community participation. These sessions should incorporate an educational component to raise knowledge and awareness of what can be provided with community palliative care.

Volunteer programs require a lot of support and resources such as funds, equipment and healthcare support. These should be planned for in advance so that volunteers can actively participate and focus on capacity building and providing palliative care. The involvement of well-known public figures, such as sportspeople and religious leaders will help strengthen the campaign. Food and fuel vouchers should be considered so that volunteers do not incur out-of-pocket costs. An online form or an app to recruit volunteers may be helpful; this app may also be used to collect credit points, travel concessions, and keep track of their volunteer hours, which may be useful for future job prospects and career opportunities.

“Adopt a grandma” initiative

This initiative aims to identify and support older people with palliative care needs. In India, caring for older people or sick family members is a cultural practice. It is the norm for grandparents to provide foster care for grandchildren; when they reach old age, the grandchildren will in turn care for them. Unfortunately, due to societal structure changes and the norms of nuclear families, there are increasingly lonely and isolated older people who require community support. Vulnerable older people may be identified by non-governmental organizations, such as Care Age India, or social services. They should be linked with volunteers, forming mobile units to visit older people for activities, companionship and social support.

Campaigns for the “adopt a grandma” initiative may be held at educational institutions, shopping malls and public events to encourage younger people to participate in caregiving. A fun component is required to garner their interest. Examples include mascots of older people characters, walking aids with race-car themes, and themed parties at college festivals. Schools also play a role in encouraging intergenerational contact; such facilitation may include writing autobiographies of older relatives for school assignments, bringing grandparents to school days, photo-sharing sessions or even showcasing skills of older family members on YouTube or TikTok.

Medical student palliative care project

In some institutions, undergraduate medical students have opportunities to carry out community outreach projects [15]. Projects that develop awareness of community palliative care can be tailored depending on the areas of need, such as older people, non-communicable diseases or rural health. These students will require a foundation in palliative care from teaching sessions, visits or study tours to palliative medicine clinics or hospices. From these

experiences, they need to plan a project, which may involve applying for funds from the medical faculty to cover costs, such as transportation.

Involvement of the palliative team is required for supervision, community liaison, public relations, and fundraising, as well as to link the students to relevant stakeholders, such as village heads, older people clubs, religious leaders or schools. Medical students in clinical years may also be able to volunteer at palliative medicine clinics, which may be student- or nurse-led, with support from other clinicians (or teleconsultations in rural areas). These project experiences should be shared at alumni meets to encourage other students to participate, and prizes or certificates can be awarded to the students for their contributions.

Workshops and training for non-communicable diseases

Patients with non-communicable diseases (NCD) may experience symptoms that benefit from palliative care, especially in advanced stages. It would be helpful to piggyback on NCD initiatives to encourage the relevant services to become more involved in palliative care [16].

The available workshops, training and information sessions for the various NCDs should be identified to decide how to incorporate palliative care. For those with multiple group sessions (for example, cardiac rehabilitation has 12 sessions per program), palliative care may contribute to one session and provide a module on symptom management or advance care planning. For NCD services providing individual counselling, such as diabetes or renal failure, separate group workshops for the clinicians may be more appropriate. These workshops may be run as train-the-trainers or a faculty development program for palliative care. Available information or pamphlets for each NCD should also be reviewed to consider adding relevant palliative care aspects, such as neuropathic pain for diabetes or dyspnoea management in lung disease. Self-assessment tools for symptoms and an action plan for exacerbations should also be provided to emphasize the importance of self-management with support.

Each NCD-affiliated society usually organizes awareness activities on commemorative days, such as World Heart Day and Diabetes Day. Providing brief information or booths for sensitization on palliative care and annual concurrent palliative care training may be considered. The main areas to focus on are symptom management in advanced disease and advance care planning, with an emphasis on supporting functional limitations and family members in the community.

Community nurses and cross-specialty collaboration

Community nurses function as leaders and champions for palliative care in many settings. There are many potential roles and abilities in improving community participation in palliative care. Nurses are well-placed to give basic palliative care training to social workers, local volunteers, health visitors and community mobilisers (whose role is mainly tracing disease and providing medications). Nurses can also empower school teachers and college students to provide health education to patients or family members. Identified clients who need palliative care may be linked by nurses to the relevant services. In nurse-led palliative care clinics, nurses and nurse practitioners provide assessments and individualized treatment plans [17].

Cross-specialty collaborations between nurses may also introduce early palliative care for inpatients, who require active involvement from various disciplines, such as critical care, oncology, geriatrics, orthopedics and neurosurgery. Patients with multimorbidity benefit from cross-referral facilities and round table discussions to ensure a consensus among clinical experts regarding management plans. Nurses are also able to provide continued support and counselling, from diagnosis, assisting with obtaining financial aid or relief funds, transitioning referring for vocational rehabilitation, all the way through grief and bereavement support. Developing community nurses and facilitating cross-specialty collaboration among nurses will help community palliative care go a long way.

Conclusions

There is a need to develop palliative care services worldwide, ideally starting within the community. Ideas and suggested approaches were provided on how to potentially improve awareness and participation in palliative care within communities.

Article information and declarations

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Author contributions

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Conflict of interest

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