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Case Study

Students as Volunteer Contingents in Palliative Care: A Case Study

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Palliative care (PC) is a service that focuses on addressing the psychological and spiritual concerns of terminally ill patients and their caregivers, not just physical symptoms. Nowadays, trained individuals, especially socially responsible students, volunteer to provide emergency services in collaboration with various organisations. This study evaluates the activities of PC student volunteers (SVs) in community engagements. This case study of Palliare, a student PC initiative, used secondary data to identify the activities of SVs in PC, the benefits to patients and their families from volunteering and the benefits of SVs. Teams of students who volunteered to provide PC acted as support systems providing psychosocial support to patients and their caregivers. Collaboration and stakeholder interaction also provided SVs with personal and professional benefits.

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INTRODUCTION

Alleviating serious health-related suffering (SHS) is a global health and equity imperative. However, global health lacks the necessary investments, interventions and indicators to ensure universal access to safe, secure and dignified care at the end of life or alleviate pain and suffering (Knaul *et al.*, 2018). Although an estimated 61 million people affected by SHS demand intensive and extended palliative care (PC), 80% cannot access it (Knaul *et al.*, 2018; Radbruch *et al.*, 2020). To close this massive disparity in access, it is essential to identify the resources to meet the demand. Besides the financial and physical resources, human resources are critical for integrating PC into the care continuum.

Before identifying the human resources engaged in PC, understanding its nature and scope is essential. The World Health Organization (WHO) defines PC as follows.

An approach that improves the quality of life of patients and their families facing the problem 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. (WHO, 2002, p. 83)

A consensus-based definition states that 'PC is the active holistic care of individuals across all ages with SHS because of severe illness and especially of those near the end of life. It aims to improve the quality of life of patients, their families, and their caregivers' (Radbruch *et al.*, 2020, p. 761).

PC is the ethical responsibility of health systems and the ethical duty of healthcare professionals (World Health Assembly [WHA], 2014). As healthcare worldwide faces resource constraints, volunteers fulfil different roles in supporting terminally ill patients, positively affecting the quality of care (Vanderstichelen *et al.*, 2018). Volunteering in PC is defined as 'the time freely given by individuals, with no expectation of financial gain, within some form of organised structure other than the already existing social relations or familial ties, with the intention of improving the quality of life of adults and children with life-limiting conditions and those close to them (family and others)' (Goossensen *et al.*, 2016, p. 186). Duties undertaken by volunteers include psychosocial care, existential care and signalling activities (Vanderstichelen *et al.*, 2018). They offer practical and emotional support and help uncover their values, beliefs and attitude to live a meaningful life. Besides, they link the terminally ill and their relatives to

the community. However, training is critical for volunteering in PC (Vanderstichelen *et al.*, 2018).

Studies comparing PC with and without volunteering confirmed that volunteer involvement was a determinant of families' satisfaction with care and that patients who received volunteer visits survived longer (Block *et al.*, 2010; Candy *et al.*, 2015; Herbst-Damm and Kulik, 2005). People choose to volunteer because of intrinsic motives, such as altruism and self-interest, and extrinsic motives, such as gaining work experience and fulfilling class requirements (Claxton-Oldfield *et al.*, 2019). Ethical principles established by the National Association of Social Workers (NASW) encourage social workers to volunteer a specific portion of their professional skills without expectation of financial return (NASW, n.d.). Professional social workers embrace volunteering as a moral value, which is professional volunteering (Jacob and Richard, 2022). Moreover, social work education through field engagements allows students to volunteer for diverse societal needs (Jacob and Richard, 2022).

Pallium India (PI) is an Non Governmental Organisation (NGO) founded in 2003 to integrate PC into mainstream healthcare with voluntary support for service delivery, capacity building, education, policy, research, advocacy and information (About Us - Pallium India | Pallium India). PI keeps community engagement (CE) at the centre and initiates CE programmes. Students' PC initiative, Students Against Needless Suffering and Pain (SANS Pain), is one of the CE programmes by PI. Also, PI provides training for student volunteers (SVs) from higher education institutions in Kerala. Under the SANS Pain project, Loyola College of Social sciences, Kerala, launched *Palliare*, in December 2021. SVs of *Palliare* take up PC as part of their CE programmes. Therefore, this study investigated the activities of SVs in *Palliare*, the benefits received by people with SHS and their families, and SVs' personal and professional gains.

METHOD

This case study analysed the secondary data, which were the reports documented by SVs in *Palliare*. The reports included their CE activities in PC, observations and gains. Data were collected after obtaining consent from the Loyola College of Social Sciences authorities. Data were collected from 100 reports by reading and locating needed information. The reports were from November 2021 to September 2022. Data were transferred to a pre-set template in MS Excel, with columns for activity, patient gain, family gain, personal gains of SV and professional gains of SV. The study result was generated by analysing the extracted data qualitatively, and finally, the results were interpreted. Three researchers completed this study in 3 months. Their discussions and expert consultations ensured the reliability of the study.

RESULTS

The CE activities of SVs in PC are shown in Figure 1. During the period under study, SVs received unit-level, district-level and university-level training. They identified the households of people with SHS in 58 *Panchayats* and conducted home visits. Medicine supplies and arranging medical check-ups were essential activities done by SVs. In addition, SVs distributed wheelchairs and walkers to the needy. They supplied groceries to the households of people availing PC. Blood donation drives and community-building programmes (CBP) were also conducted. Under CBP, SVs conducted awareness sessions on PC in the community, and they aided medicine supplies and medical check-ups from primary health centres and PC units.

Based on their observation and interaction with PC beneficiaries and their family members, the SVs documented the benefits to the patients and their families from the services of the SVs. Volunteer visits helped patients share their feelings, worries and anxieties. The presence of volunteers was a relief to the patients. The supply of medicine helped them to continue the medicine without interruption. In addition, mobility assistants have improved their lives by enabling them to move easily without the help of their caregivers.

Patients' families received better ideas about care and substantial support in care. Medicine distribution and medical check-up arrangements reduced their burden. Moreover, grocery supply was instrumental support for financially troubled families. The supply of mobility aids reduced the caretaker burden considerably. Surveys allowed them to share their needs, which the governments must address.

Apart from the gains that patients and their families received, SVs also benefitted from their services in PC. Table 1 shows the professional and personal gains of SVs.

SVs developed a sense of social responsibility towards people needing care and service. They recognised Palliative

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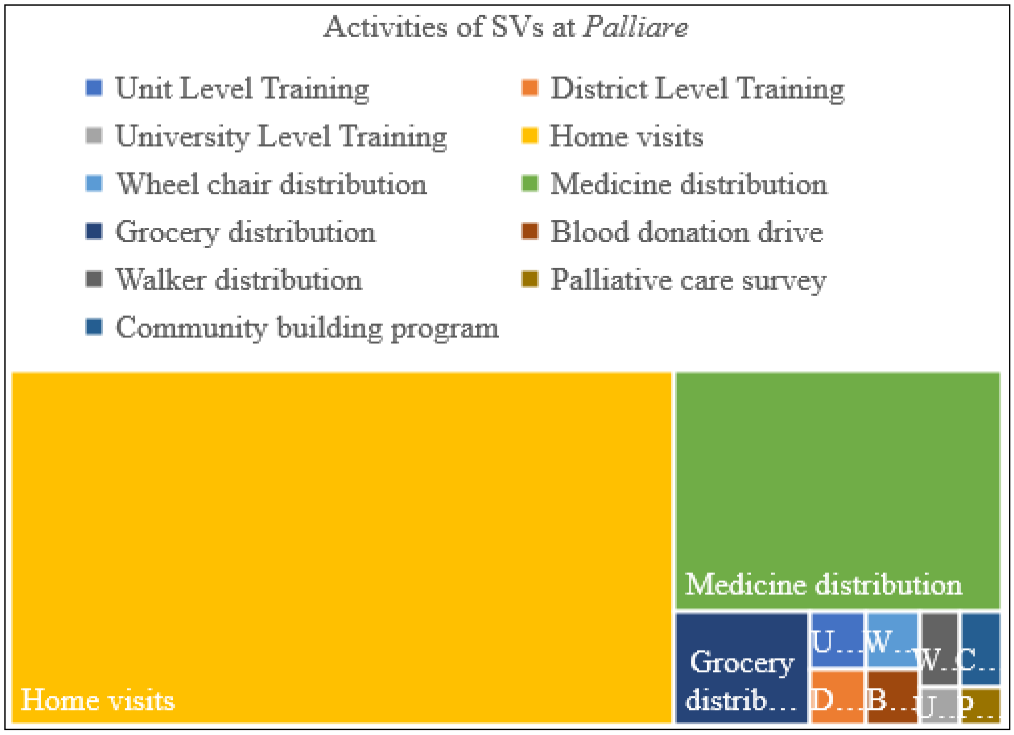


Figure 1. Activities of Students Volunteers at *Palliare*

Table 1. Gains of Students Volunteers

Professional gains	Personal gains
• Experience in CE	• Sense of social responsibility
• Knowledge of PC and its dimensions	• Increased concern for fellow human beings
• Role identification in palliative care	• Improved perception of the value of health
• Skill to use tools such as psycho-social assessment, socioeconomic survey, needs assessment, and resource mobilisation	• A reality-based view of the world
• Developed empathic relationship	• Strengthened relationships
• Care plan development skill	
• Interaction and networking with local government	
• Knowledge of stakeholder management	
• Service gap identification	
• Fundraising practice	
• Documentation skill	
• Fulfilment of course requirement	

services as the duty of volunteers actively involved in the community services, community collaborations and initiatives of PC organisations operating in rural and urban areas. They could interact with people under PC, family members and carers and provide ongoing psycho-social support.

The possibilities of raising funds to manage the need of beneficiaries which were introduced with successful examples, helped the students to know about the community. The need for follow-ups with palliative patients was introduced through awareness sessions. The students developed a knowledge base, specifically systematic service knowledge about services, symptoms, treatment and family and social support. Students could identify various dimensions of PC and their individualistic role in the pain and PC field.

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SVs developed their skills in assessment, service gap identification, networking and documenting. Besides, they achieved area-specific skills for care plan development and care management. Collaboration with local self-government and other agencies helped them to carry out signalling functions effectively. Moreover, volunteering in PC finetuned them into better humans.

CONCLUSION

The study highlights that volunteering in PC can have a meaningful and satisfying impact as it helps increase practical knowledge and CE. SVs have a unique and vital role to play in the affairs of poor people who find accessibility to PC difficult. Volunteers can help palliative patients by equipping them to meet their physical, psychological, social and financial needs. To ensure the availability of human resources as PC volunteers in the future, it is essential to inform individuals about the benefits of volunteering in PC in public forums. In addition, collaborations should be systematically incorporated into the public healthcare delivery system. Finally, this study recommends more in-depth studies on student volunteering in service delivery and programme planning.

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