

Addressing insufficient access to palliative care: what stakeholders can do?

Abstract

Health care providers look at palliative care (PC) as an approach that “improves the quality of life of patients (both adult and children) and their families who are facing problems associated with life-threatening illness”. It has been, on the basis of findings of large-scale clinical trials, found that PC has the potential to prevent and relieve suffering through the early identification, correct assessment and treatment of pain and other problems (whether physical and/or psychosocial in nature). Author of this research essay argues that adequately addressing suffering (resulting from pain) involves taking care of issues that are beyond physical symptoms. However, it is pertinent to note that significant proportions of population in many regions of the globe (who are in need) do not have adequate to PC owing to several factors. It is against this backdrop that the author of this work primarily aims to present an insight into strategic interventions required for adequately addressing insufficient access to PC. In terms of methodology, secondary data (largely ‘quantitative’ in nature) have been used, and method of data analysis is descriptive (involving “desk-based research”). This work briefly includes that addressing practical needs form priority on health developmental initiatives, with specific focus on “offering a support system to help patients live as actively as possible until death”.

Keywords: palliative Care (PC), intervention areas, stakeholders, cooperation, networking collaboration

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Introduction

Under the framework of Sustainable Development Goals (SDGs) 2030, PC is globally recognized as the human right to health. The data published by the World Health Organization (WHO) in 2023 in the document titled Palliative Care; it has been argued that PC should be provided through “person-centered and integrated health services”. This mechanism, says, has potential to pave way for meeting specific needs and preferences of individuals.¹ The author of this research paper argues that PC, in the present day situation, is need of the hour for addressing a wide range of diseases among people from across the regions of the planet. Interpretations of WHO data contained in the above outlined publication indicates that majority of global adult population who are in specific need of PC are encountered with chronic diseases [such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%)]. In this very context, it is significant to note that several other contributing factors may also necessitate PC. Such key factors include (a) kidney failure, (b) chronic liver disease, (c) multiple sclerosis, (d) Parkinson's disease, (e) rheumatoid arthritis, (f) neurological diseases, (g) dementia, (h) congenital anomalies, and (f) drug-resistant tuberculosis.²

Research methods

This section on research methods presents information on (a) context (rationale), (b) objectives, (c) type and sources of data used, (d) methodology of data analysis, (e) scope, and (f) significance. Discussion follows:

Context (Rationale)

As outlined in introductory part of this work, initiatives aimed at enhancing PC care programs enhance the quality of life of patients. It has been established that such interventions also offer helping hand to the patients' families who, often, are face challenges connected with life-threatening illness. Notably, illness may be witnessed in the form of physical, psychological, and social disorders. At the same time, overall quality of life of caregivers improves. There is, thus, need to provide adequate PC (also termed as “supportive care” in India) to all,

especially to those who are in urgent need for this type of services.³ The author argues that this description rationalizes need of this research essay.

Objectives

Prime objective of the submission is to present an insight into strategic interventions required for adequately addressing insufficient access to PC, for all (and at all times). Also, the author has proposed framework within which (a) specific stakeholder groups and settings can be identified, and (b) effective PC care services can be ensured. Appropriate and relevant examples have been quoted in support of research statements made in this research work.

Type and source of data used

Data obtained from secondary sources have been used by the author in the present work. They (secondary data) have been collected from sources, such as books, book chapters, journals, and internet resources. However, data published from only reliable sources (such as government publications and research findings brought out by international agencies and publishing houses) have been used. Data sources have presented under reference section; sources appear in same order in which they are quoted (and indicated) in the text. In terms of type, data used are mostly ‘qualitative’ in nature. Additionally, the development of this report benefitted from inputs of experts who are in the network of the author.

Methodology of data analysis

With regard to methodology of analysis employed in this work, nature of analysis is ‘descriptive’ that involves “desk-based research”. Qualitative data (collected from secondary sources, as outlined under above section on type and sources of data used) have been analysed in descriptive manner; data analysis method does not involve statistical (mathematical) methods and techniques. Examples of appropriate and relevant initiatives have been quoted in the research. The terms research paper, research work, work, and research essay have been used interchangeably by the author, they all carry the same meaning.

How data was collected and analyzed

This section touches upon (a) the method that was used to collect the data, and (b) how the collected data was analysed. In terms of ‘qualitative’ vs. ‘quantitative’ methods, data taken in this research are largely in the form of words, indicating qualitative data. As outlined in previous section (under Research Methods), the author has used secondary data; original (primary) data was not collected since scope and objectives (of the present research) does not require application of this method. For the purpose of qualitative data analysis, the author used methods such as thematic analysis to interpret patterns and meanings in the data to meet desired results.

Scope

In terms of scope, the author says that this piece of brief research paper offers meaningful (and relevant) systematic and scientific information on aspects of the intervention areas wherein stakeholders need to focus on. The findings will serve as guiding principles for them (stakeholders) in meeting the gaps in insufficient access to PC.

Significance and Limitations

In terms of significance, this work presents description on what stakeholders can do in designing and implementing more effective PC programs. The author presents two limitations. First, the research does not carry information on “review of literature”, as required in authoring research reports. This has resulted from the fact that after extensive search, the author did not find many scientifically researched papers (publications) that can form part of review of literature. Second, plagiarism can be detected to some extent (up to 5%), in the work (which is not permitted in line with standard academic and research code of conduct). The author presents this argument for this: if changes are made beyond certain limit while presenting some key facts (including figures in statistical forms), the intended meaning is lost. All possible precautions have been taken by the author to adhere to plagiarism rules. All sources have been quoted, both in the text and under references. Wherever required and possible, before submission of this paper, authors and publishers have been informed (by email letters) about data use.

Discussion

Significance of Stakeholders’ Involvement

This section of the work outlines what stakeholders can do in addressing insufficient access to PC. For the purpose of this work, the terms ‘stakeholders’ has been defined as “*a person, group (or organization) with a vested interest, or stake, in the decision-making and activities of a business establishment, an organization or project*”. Before presenting discussion on significance of stakeholders’ involvement, the author finds it appropriate to briefly discuss the conceptual quality of very meaningful contribution of stakeholders working at different levels in making PC initiatives success in true sense. In this context, the author says that considerations for implications for practice; theory (and or policy) requires that different methods of stakeholder involvement may (should) be required for different PC stakeholder groups in different socio-economic and demographic settings. Further, lay and professional stakeholders’ involvement in PC initiatives is both ‘feasible’ and ‘worthwhile’ during early stages of program development. It is pertinent to note that this institutional arrangement has the potential to identify key issues from the perspectives of service users and providers. Furthermore, guidance for stakeholders’ involvement in PC research is needed in order to ensure that initiatives in policy and service development sectors are more responsive to the needs of service (a) ‘users’, and (b) ‘providers’.⁴

The author, at this juncture, goes one step ahead by saying that stakeholders in the health-sector, in general, and in providing PC care, in particular, can be members of the health-based organization.⁴ The author presents discussion by saying that findings of research studies are indicative of enhanced effectiveness of PC care with active stakeholders’ involvement. Stakeholders in the health-sector can also make improvements in two prime areas, namely, (a) research development, and (b) dissemination of relevant awareness-based information among the target group. The second listed area can be facilitated by undertaking community level actions, such as lecture series, audio-visual shows, etc. The author does not wish to further elaborate on this aspect as it is beyond the scope and objective of this work.⁵ At international academic events, organized by the WHO and other specialized agencies of the United Nations (UN), significant amount of debate and discussion has taken place to develop modalities for stakeholders’ engagement in PC care. Also, the issues of methods and scientific tools needed for evaluating stakeholders’ level of engagement have been extensively debated into.⁶ The author presents below the proposed framework within which (a) specific stakeholder groups and settings can be identified, and (b) effective PC care services can be ensured.

In implementation of programs with focus on PC care, monitoring and evaluation (M&E) forms the key. The implementation of M&E requires the involvement of different stakeholders and the definition of their roles in assessing PC initiatives (at both macro and micro levels). For better outcomes, stakeholders, consisting of technical staff, policy-makers, researchers, health-care professionals, civil society groups, non-governmental organizations (NGOs), funding agencies need to be linked with planning and implementation of the monitoring process.⁶ Stakeholders are expected to fulfil one or more of the following functions: *Indicator selection*: Stakeholders need to be careful in selection of indicators (in view of adaptation to prevailing different local contexts). The process may include analysis of partners’ capacities (in terms of availability of resources infrastructure). Actively involving (key) stakeholders in selection of indicators will help decision-makers understand (1) important feasibility considerations, and (2) way forward for increasing the probability of effective implementation of PC programs at national and regional (sub-national levels).⁷

- a. Raising awareness: It is important to focus on awareness creation among the target population (or specific sector needing priority attention. Policy makers need to work (and collaborate) with stakeholders with the objective of building shared understanding of the importance of data collection (and its analysis) in PC.⁸ According to considered research view of the author, collaborative and joint initiatives gain increased significance. However, this will require motivation and empowerment on the part of stakeholders. This, in turn, will ensure their meaningful participation needed for information management (IM).⁷
- b. Collection and analysis of data (information): This is another area of concern. Policy makers suggest that collection, compilation and analysis of PC data require coordinated efforts between all those who are involved. They may include (1) health authorities; (2) government institutions; (3) members of civil society; and (4) PC patients, caregivers, and their family members. Structures, processes, policies and procedures need to be put in place in order to (1) maintain data quality, and (2) prevent errors in interpretation and analysis.⁷
- c. Accountability: It has been found that it is good idea to involve a variety of stakeholders in (1) reviewing the progress made, (2) implementing indicators (and outputs) derived from the indicators. Importantly, from program management point of view, the involved stakeholders can enable policy makers (1) ensuring accountability to the process, (2) identifying actions

and strategies needed to consolidate M&E process, and (3) strengthening components of PC activities at community, national and (or) regional levels.⁷

Suggested Model

The author, in this section, attempts to present “palliative care development conceptual model”. This approach has potential benefits of connecting with the “operational framework for primary health care”. This working mechanism enables stakeholders transform “conceptual vision” into “actual action” at the ground situations. This framework envisages (and focuses) on three key elements:

- a. Designing policies to guarantee resources, and multi-sectoral actions pertaining to (1) education, (2) empowerment, and (3) research.
- b. Implementing integrated health services at community levels, especially in strategic indicators.
- c. Empowering people at large and community engagement.⁹

The author says that all activities (outlined above under each key element (area) are in line with enhancing coverage of population in health matters, in general, and in offering PC services, in particular. Significantly, this model can be tested upon by involved stakeholders at the global, national and sub-national levels in order to guide improvement in PC services.⁹ However, considerations of locally prevailing socio-economic and demographic characteristics need to be taken into account by the stakeholders at the stage of program design and implementation (including M&E). The model needs to be understood as “fostering the capacity for action and decision of individuals, families and communities in order to promote their health and well-being”.

Within the framework of institutional working mechanism and in the context of adaptation of the above suggested model, the author says that several inter-governmental agencies [including the World Health Organization (WHO)], have addressed the issue of PC through several academic & research platforms. Importantly, from findings of studies on the subject of assessment of higher education learning outcomes (AHELO), appropriate lessons can be learnt.¹¹ From adaption point of view, health care providers are of the considered research view that international and national developmental groups, collaborators, and other agencies [for instance, the WHO, and the World Palliative Care Alliance (WPCA)] are engaged in grass-root level initiatives that are primarily aimed at (a) promoting activism; (b) monitoring the progress made in PC; and (c) providing resource support on education and policy fronts. The palliative care development conceptual model has been found to be adapted and conceptualized in nations that are (designing) developing and implementing PC at community levels. Importantly, these PC entities and initiatives in the health-sector have declared a call for “action and international collaboration” (AIC) for the purpose of advancing the global status of PC.¹²

Conclusions

This work aimed to provide concrete modalities to involve stakeholders at various levels in development of palliative care and address gaps in a timely manner. The author concludes that addressing the issue of insufficient access to palliative care should be priority agenda for health care providers. Equally significant is a stakeholder-engaged process; it can help address and refine key aspects associated with palliative care.¹⁰ It is due to these considerations that several countries have taken appropriate steps in this direction. Canada, e. g., has, over the years, has focused on improving access to palliative care for its citizens. However, these initiatives at national and sub-national levels require a “focused collective effort” towards palliative and end-of-life care advocacy and policy. Another area

for consideration, according to the author, is: “identification of stakeholders”. This mechanism is an important step for to ensuring that “efforts to improve palliative care are coordinated” in the process of actual program implementation.¹²⁻¹⁴ Further, improving access to palliative care for, for all in need, and at all times, requires a focused collective effort towards palliative and end-of-life care advocacy and policy. Furthermore, in terms of way forward and future directions, the author suggests undertaking intensive research by the academic and (collaborative) research community with the prime objective of finding meaningful ways that have potential to ensure required access to palliative care for all on the planet.

On the basis of data presented in previous sections, the author is of the view that quality improvement interventions have succeeded in improving the quality of PC delivery. In-depth and cross-sectional research studies are needed on specific quality improvement types in PC. More specifically, the author [in his individual capacity as Independent Researcher (Scholar), post-retirement from the S. N. D. T. Women’s University (located at Mumbai, India)] of this research paper recommends including organizational change and multiple types of interventions within the framework of PC studies.

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Conflicts of interest

The authors declare that there are no conflicts of interest.

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