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Substantial Shift in Palliative Care from Hospice to Community and Its Integration into Community-Based Primary Health Care

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ABSTRACT

In 1967 Cicely Saunders founded St. Christopher's Hospice. Then, Saunders' hospice model of palliative care promoted palliative care movement in the world. World Health Organization (WHO) adopted this hospice model, but WHO has gradually improved palliative care and integrated it into community-based comprehensive care. This review focuses on the recent substantial shift in palliative care from hospice to community and WHO's leadership in integration of palliative care into primary health care. We summarized Saunders' hospice model, WHO's improved model in 2002 and the complemented model proposed by the International Association for Hospice & Palliative Care (IAHPC) in 2019. Then, we delineated the development steps of WHO's integration of palliative care into primary health care. We also showed integration of supportive care in cancer and existential therapy/care into primary health care. Thus, various limitations of Saunders' hospice model (palliative care for patients with cancer only at the terminal stage and Christian religious care) have been overcome by WHO's integrated primary health care model that provides care for noncommunicable (including cancer) and communicable diseases during all the continuity of care. Further education and training of the participants in community-based primary health care are required to address all the needs of patients and families in community.

Keywords
Community, Existential therapy, Palliative care, Primary health care, WHO.

Introduction

Modern palliative care began in 1953 with the first prescription of opioid for cancer pain control by John Bonica in 1953 [1]. This monumental first step gradually accelerated the idea and practice of palliative care in clinical medicine. For instance, in 1967 Cicely Saunders founded St. Christopher's Hospice in South London [2]. This influential hospice-based palliative care model promoted and disseminated palliative care movement in all the world [1]. World Health Organization (WHO) later adopted the essentially identical palliative care model in its second edition of palliative care definition [3]. However, WHO has gradually integrated palliative care into community-based primary health care successively by the Resolution WHA62.12 in 2009 [4], the Resolution WHA67.19 in 2014 [5], the Resolution WHA69.24 in 2016 [6] and the Declaration of Astana in 2018 [7]. This WHO's primary health care model was complemented by the Consensus-based definition of palliative care definition by the International Association for Hospice and Palliative Care (IAHPC) in 2019 [8,9]. Furthermore, supportive care in cancer [10,11] and existential therapy/care [12-18] have enriched palliative care and primary health care.

This review article focuses on the recent substantial shift in palliative care from hospice to community and WHO's leadership in integration of palliative care into primary health care. We also show the concomitant integration of supportive care in cancer and existential therapy/care into community-based comprehensive primary health care.

Hospice Model of Cicely Saunders

The historical development of palliative care reflects the

substantial differences between the traditional hospice model and the community-based comprehensive model (Table 1). The aim of the hospice establishment by Saunders was to provide physical pain control for patients with cancer [2,19] at the terminal stage [20]. In addition, her ideal of the care for 'total pain' — physical, mental, social and spiritual pains [21] was also realized in her St. Christopher's Hospice. Saunders mentioned the Christian foundations of early hospice [22] and St. Christopher Hospice was maintained in its Christian background [23,24]. Thus, Saunders' spiritual care was essentially based on Christian religious care [25,26]. Saunders also pointed out the necessity of team approach in her hospice palliative care [27]. Therefore, end-of-life care for patients with cancer at the terminal stage [20] and Christian religious care (spiritual care) [22,24,25] characterize Saunders' original hospice model.

Hospice Model Improved by WHO (2002)

The definition of palliative care in 2002 by WHO [3] well reflects this historical development of palliative care: "Palliative care is 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." However, WHO added three improvements, i.e., 1. Early identification of symptoms, 2. Bereavement care for patient's family, and 3. Application of palliative care in conjunction with conventional anticancer therapies. These three improvements are also succeeded by IAHPC's definition in 2019 [8]. Early integration of palliative care into oncology care and concurrent care with cancer treatments such as cytotoxic chemotherapy or radiation therapy have been rather promoted by supportive care in cancer [28-32]. This means that the restriction to end-of-life care in the traditional hospice model of palliative care has been overcome by WHO [3] and supportive care in cancer [10,11].

Consensus-Based Definition of Palliative Care of IAHPC (2019)

The palliative care redefined by IAHPC in 2019 [8,9] also seems to reproduce the almost identical definition: "Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to 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." The three improvements of palliative care definition by WHO [3], i.e., early identification of symptoms, bereavement care and concurrent palliative and anticancer care, were reproduced. IAHPC [8] further added 1. The care for severe illness of 'any acute or chronic illness and/or health condition,' 2. The term 'holistic' care, 3. The respect for 'the cultural values and the beliefs,' 4. The care 'throughout course of an illness, 5. The referral and consultation to a multiprofessional team, and 6. The care 'throughout all the health care settings (place of residence and institutions) and in all levels (primary to tertiary).' The last proposal explicitly indicates the necessity of community-based comprehensive care because 'palliative care is part of all health services (from community health-based programs to hospitals).' In this sense, the palliative care definition of IAHPC concomitantly incorporates and promotes WHO's intention to integrate palliative care into primary health care [4,5]. In other words, it substantially complements and improves the definition of WHO in accordance with WHO's recent worldwide leadership in integration of palliative care into community-based primary health care [33-38]. Thus, the consensus-based definition of palliative care of IAHPC offers a holistic and prospective point of view in the new era of palliative care.

Differences between Hospice Model and Community-Based Comprehensive Model

In fact, there are substantial differences between traditional hospice model and community-based comprehensive model (Table 1). In the traditional hospice model as in Japan, palliative care is provided for patients with malignant diseases at the terminal stage by the multiprofessional palliative care specialist team [39,40]. On the contrary, in community-based comprehensive model, care is provided for patients with all the diseases across all the continuity by the multidisciplinary team in all the care levels from primary to tertiary [4,5,8,35]. Saunders [27], WHO [3] and IAHPC [8] refer to the team approach. The team of the advanced multiprofessional approach in hospice consists of palliative medicine specialist doctor, palliative care specialist nurse, social worker, psychooncologist (psychiatrist), psychologist, chaplain, physical therapist, occupational specialist, dietitian and pharmacist [41-44]. It should be noted that the care for 'total pains' is provided by different specialists, i.e., control of physical pains by palliative medicine specialist doctor, care for mental distress by psychiatrist/psychologist, solution of social needs by social worker, and spiritual care by chaplain. This complexity may cause several problems in multiprofessional palliative care setting [45,46]. The multidisciplinary team approach in community-based comprehensive care should be distinguished from the multiprofessional team approach in hospice and hospitals [44]. However, the multidisciplinary settings in community-based primary health care are flexible and vary according to the needs of patients and families in each community. The complicated multidisciplinary settings in community-based primary health care will be later presented.

Table 1: Differences between the Traditional Hospice Model and the Community-Based Comprehensive Model.

Models	Diseases	Continuity	Team approach
Traditional hospice model	Malignant diseases	Terminal stage alone	Multiprofessional
Community-based comprehensive model	All the diseases	All the continuity	Multidisciplinary

WHO's Leadership in Integration of Palliative Care into Primary Health Care

According to WHO [35], its focus on primary health care has a long history since the Declaration of Alma-Ata in 1978 [47]. Its definition of primary health care covers promotive, preventive, curative and rehabilitative services (Table 2), but there is no reference to

palliative care. WHO's intention to integrate palliative care into community-based primary health care is clearly recognized in the Resolution WHA62.12 on Primary health care, including health system strengthen in 2009 [4], because WHO added palliative care to comprehensive primary health care services (Table 2). Furthermore, in the Resolution WHA67.19 on Strengthening national health emergency and disaster management capacities and resilience of health systems in 2014 [5], WHO emphasized the primary health care for noncommunicable diseases. In addition, in the Resolution WHA69.24 on Strengthening integrated, people-centered health services in 2016 [6], WHO mentioned health sector and intersectoral collaboration, and defined a holistic approach as 'services, including health promotion, disease prevention, diagnosis, treatment, disease-management, rehabilitation and palliative care services' The term 'holistic' would be reiterated by the palliative care redefinition of IAHPC [8] and Oluyase et al. [44]. Finally, in the Declaration of Astana in 2018 [7], WHO indicated the importance of primary health care in the framework of universal health coverage (UHC) as a comprehensive services and care (Table 2). Thus, a simple concept of primary health care in the Declaration of Alma-Ata in 1978 [47] has gradually developed through integration of palliative care to holistic and comprehensive care in the framework of universal health coverage [4-7,34-36].

Accordingly, WHO has defined several terms around community-based primary health care (Table 3), including community [37], community health centre (CHC) [35], community health worker (CHW) [35], continuity of care [34], Health in All Policies (HiAP) [48], integrated health services [37], people-centered care [34], person-centered care [34], primary care [34], primary health care (PHC) [37] and universal health coverage (UHC) [37]. Concerning CHC, WHO's definition [35] seems to cover only minimum participants (Table 3). We will later discuss extended primary health care settings.

Continuity and Diseases

In accordance with the development of WHO's integrated community-based primary health care, continuity of care and applied diseases have remarkably extended (Table 4). The original hospice model of Saunders [2] limited its palliative care for patients with cancer at the terminal stage. The malignant diseases that are frequently found today and require specialist palliative care are shown in Table 4. WHO's improved palliative care definition in 2002 indicated necessity of early identification of cancer pain and symptoms [3]. This is a proposal for extended application for early stage of cancer. Accordingly, the continuity of supportive care in cancer encompasses all the stage, i.e., cancer risk assessment; cancer prevention; early detection of cancer; cancer diagnosis; cancer and comorbidity treatment, pain control, symptom management; posttreatment surveillance; and end-of-life care [49-52]. In 2013, WHO clarified its global action plan for the prevention and control of noncommunicable diseases (cancer and non-cancer chronic diseases) [53]. Care for noncommunicable diseases was reproduced by the Resolution WHA64.12 in 2014 [5]. WHO enumerates various non-cancer chronic diseases (Table 4) [53-55]. In the framework of universal health coverage proposed by the Declaration of Astana in 2018 [7], WHO indicated the necessity of primary health care during all the continuity for noncommunicable (including cancer) and communicable diseases (Table 2). WHO's aim of this declaration was 'to meet all people's health needs across the life course through comprehensive preventive, promotive, curative, rehabilitative services and palliative care.' This was a final integration of palliative care into universal health coverage. Thus, the limitation of Saunders' original hospice model, i.e, patients for cancer and terminal care, have been overcome by the successive improvements and integration of palliative care into primary health care by WHO [33-36].

Existential Therapy and Spiritual/Religious Care

Community-based specialist palliative care physicians alleviate physical, psychological and existential/religious pains in terminal care [39,40,56-58]. Frequently observed physical symptoms among patients with cancer at the terminal stage are cancer pain, malnutrition, dehydration, anemia, dyspnea, fatigue and pressure ulcer [39,40], while depression, anxiety, insomnia and delirium are remarkable psychological/psychiatric symptoms [39,40]. However, among palliative care specialists, there has been a long-term confusion around spiritual care, because existential care and spiritual/religious care have been not well distinguished, although

Table2: Development of WHO's primary health care.

WHO's documents	Definitions	References
Declaration of Alma-Ata in 1978	Primary health care addresses the main health problems in the community, providing promotive, preventive, curative and rehabilitative services accordingly.	[47]
Resolution WHA62.12 in 2009	Comprehensive primary health care services, including health promotion, disease prevention, curative care and palliative care.	[4]
Resolusion WHA67.19 in 2014	Palliative care is an integral component of all relevant global disease control and health system plans, including those relating to noncommunicable diseases and universal health coverage, as well as being included in country and regional cooperation plans.	[5]
Resolusion WHA69.24 in 2016	Coordination of health services within the health sector and intersectoral collaboration in order to address the broader social determinants of health, and to ensure a holistic approach to services, including health promotion, disease prevention, diagnosis, treatment, disease-management, rehabilitation and palliative care services.	[6]
Declaration of Astana in 2018	We promote multisectoral action and universal health coverage (UHC). … Primary health care (PHC) will provide a comprehensive range of services and care, including but not limited to vaccination; screenings; prevention, control and management of noncommunicable and communicable diseases; care and services that promote, maintain and improve maternal, newborn, child and adolescent health; and mental health and sexual and reproductive health.	[7]

Table 3: WHO's definitions of the terms around primary health care.

Term	Definition	References
Community	A unit of population, defined by a shared characteristic (for example, geography, interest, belief or social characteristic), that is, the locus of basic political and social responsibility, and within which everyday social interactions and most life activities of the people takes place.	[37] p. viii
Community health centre (CHC)	Nurse and possibly also a doctor, social worker or lay counsellor with basic training in palliative care provide outpatient care and possibly home visits as needed.	[35] p. 31
Community health workers (CHW)	CHWs are members of the community where they work, should be selected by the community, should be answerable to the community for their activities, should be supported by the health system but not necessarily be a part of it, and have shorter training than professional health workers.	[35] p. 78
Continuity of care	The degree to which a series of discrete health care events is experienced by people as coherent and interconnected over time and consistent with their health needs and preferences.	[34] p. 8
Health in All Policies (HiAP)	An approach to public policies across sectors that systematically takes into account the health implications of decisions, seeks synergies, and avoids harmful health impacts in order to improve population health and health equity.	[48] p. 2
Integrated health services	The management and delivery of health services so that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation and palliative care services through the different functions, activities and sites of care within the health system.	[37] p. viii
People-centred care	An approach to care that consciously adopts the perspectives of individuals, carers, families and communities as participants in and beneficiaries of trusted health systems that are organized around the comprehensive needs of people rather than individual diseases, and that respect social preferences.	[34] p. 8
Person-centred care	Care approaches and practices in which the person is seen as a whole, with many levels of needs and goals, the needs being derived from their personal social determinants of health.	[34] p. 8
Primary care	The provision of integrated, accessible health care services by practitioners who are accountable for addressing a large majority of personal health care needs, developing sustained partnerships with people, and practicing in the context of the family and community.	[34] p. 8
Primary health care (PHC)	A whole-of-society approach to health that aims to maximize the level and distribution of health and well-being through three components: (i) primary care and essential public health functions as the core of integrated health services; (ii) multisectoral policy and action; and (iii) empowered people and communities.	[37] p. viii
Universal health coverage (UHC)	Ensured access for all people to needed promotive, preventive, resuscitative, curative, rehabilitative and palliative health services, of sufficient quality to be effective, while also ensuring that the use of these services does not expose any users to financial hardship.	[37] p. ix

Table 4: Extension of continuity and diseases in the development of integrated palliatie care and primary health care.

Models	Continuity	Diseases
Hospice model of Saunders in 1967 [2]	Terminal stage of cancer	Malignant diseases (colorectal cancer, gastric cancer, pancreatic cancer, malignant intraductal papillary mucinous neoplasm of the pancreas, hepatocellular carcinoma, lung cancer, breast cancer, ovarian cancer, prostate cancer, renal cancer, etc.)
Palliative care improved by WHO in 2002 [3]	Early stage of cancer	Malignant diseases (as shown above)
Integrated primary health care in 2013 [53-55]	Chronic stage of noncommunicable diseases	Noncommunicable diseases (cancer, cardiovascular diseases, chronic obstructive lung disease, interstitial pneumonia, drug-resistant tuberculoais, diabetis mellitus, chronic kidney disease/renal failure, chronic liver disease, rheumatoid arthritis, Parkinson's disease, dementia, multiple sclerosis, other neurological diseases, etc.)
Declaraton of Astana in 2018 [7]	All the continuity	Noncommunicable (including cancer) and communicable diseases

these are essentially different [14,15,52,59-61]. Fortunately, the distinction between existential and religious/spiritual distress has been gradually recognized [62-64]. Thus, the historical limitation of spiritual care to Christian religious care [2,22-25] has been partly improved. However, even today, spiritual/religious care is provided mainly by chaplain in hospice [65,66]. In contrast, existential therapy that was founded by Viktor E. Frankl [12-15,67] has been succeeded by various psychotherapists, psychiatrists and palliative care physicians [17,18,67-72] for patients with cancer or non-cancer diseases across the continuity of care. Symptoms of existential distress (loneliness and isolation; hopelessness; meaninglessness; and loss of autonomy) [13,17,67,72-75] are caused by lack of meaning in life [12,13,17,67,69,70,72]. Indeed, community-based primary health care is suitable to provide existential therapy/care for patients with noncommunicable diseases (including cancer) during its long-term care.

Discussion

Today, due to WHO's leadership, palliative care has been integrated into community-based comprehensive care as its essential part. The most remarkable advantage of community-based primary health care is its capability to provide care for noncommunicable (including cancer) and communicable diseases during all the continuity of care [4,5,7]. In particular, long-term care and end-of-life care for patients with dementia are well suited to community-based primary health care [76-78]. In addition to the noncommunicable non-cancer diseases indicated by WHO [53-55] in Table 4, parkinsonian syndrome [79] (dementia with Lewy bodies, multiple system atrophy, corticobasal degeneration and

progressive supranuclear palsy), immune thrombocytopenia [80], myelodysplastic syndrome [81] and intraductal papillary mucinous neoplasm of the pancreas [82,83] are important and not rarely found chronic diseases for long-term palliative care in the community-based primary health care settings [84]. Furthermore, community-based primary health care can also provide care for orthopedic diseases (lumber and cervical spinal canal stenosis, osteoarthritis of knee joints, periarthritis scapulohumeralis, carpal tunnel syndrome, osteoporosis, ossification of posterior longitudinal ligament and distortion of hoot joints), mild rheumatological disorders (Sjögren syndrome, polymyalgia rheumatica, myofascial pain syndrome and fibromyalgia), dermatological diseases (phlegmon, scabies, skin abscess, paronychia, insect byte, psoriasis and pressure ulcer), allergic diseases (allergic dermatitis, lichen, allergic rhinitis, allergic conjunctivitis and anaphylaxis), pulmonary diseases (asthma, asthma-COPD overlap syndrome, acute pneumonia and aspiration pneumonia), cardiovascular diseases (hypertension, angina pectoris, myocardial infarction, atrial fibrillation, supraventricular premature contracture, ventricular premature contracture, WPW syndrome, atrioventricular block, pericarditis, obstructive arteriosclerosis and deep vein thrombosis), cerebrovascular diseases (cerebral infarction, cerebral hemorrhage, subarachnoid hemorrhage and subdural hemorrhage), gastroenterological diseases (gastric ulcer, duodenal ulcer, gastroesophageal reflux disease, colon polyp, acute/chronic pancreatitis and acute/chronic hepatitis), hyperlipemia, hyperuricemia, hyper- and hypothryroidism, anemia (renal anemia and anemia due to gastrointestinal hemorrhage), mild psychiatric diseases (mild depression, anxiety disorder and insomnia) and other communicable diseases (COVID-19, tonsillitis and urinary tract infection).

Another important contribution of primary health care to supportive care in cancer is early detection of cancer [49-51] by image screening (breast cancer, lung cancer, pancreatic cancer, liver cancer, prostate cancer and skin cancer) [85] and screening by tumor markers, including α-fetoprotein (hepatocellular carcinoma, germ cell tumor), β2-microglobulin (multiple myeloma), β-chorionic gonadotropin (choriocarcinoma, germ cell tumor), CA125 (ovarian, lung, endometrial cancers), CA15-3 (breast cancer), CA19-9 (pancreatic, biliary tract, colorectal, gastric, ovarian cancers), CA72-4 (gastric, ovarian cancers), calcitonin (thyroid medullary cancer), CEA (colorectal, gastric, esophageal adenocarcinomas, non-small cell lung cancer, breast cancer), chromogranin A (neuroendocrine tumors), CYFRA21-1 (non-small cell lung cancer), Her-2-neu (breast cancer), HE-4 (ovarian cancer), NSE (neuroendocrine tumors, small cell lung cancer), proGRP (small cell lung cancer), PSA (prostate cancer), S100 (malignant melanoma), SCC (squamous cell carcinomas), and thyroglobulin (thryroid cancer) [86]. In this sense, supportive care in cancer has been also integrated into WHO's comprehensive primary health care.

According to WHO [35] in Table 3, the minimum participants of community health centre consist of doctor, nurse and social worker/lay counsellor. However, in real settings of community-based primary health care, more members participate in community-based comprehensive care. For instance, at Kami town in Japan, a monthly meeting of case studies is held by an extended community-based multidisciplinary team, including palliative care specialist (or basic palliative care trained) general physician, dentist, nurse, care manager, specialist care workers, representatives of nursing home for the aged and specialists from the Kami town office. This may be a multisectoral collaboration. In addition, visiting nurse supports home care, and a system of quick referral to primary, secondary and tertiary institutions is established and maintained within the district.

Conclusion

The substantial shift in palliative care from hospice to community has been accelerated by WHO's leadership in integration of palliative care into community-based primary health care. Various limitations of Saunders' hospice model (palliative care for patients with cancer only at the terminal stage and Christian religious care) have been overcome by WHO's integrated primary health care model that provides care for noncommunicable (including cancer) and communicable diseases during all the continuity of care. Supportive care in cancer and existential therapy/care have been also integrated into comprehensive primary health care. However, further education and training of the participants in community-based primary health care are required to address all the needs of patients and families in community.

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