A Call for Integrated and Coordinated Palliative Care

Kevin Brazil, PhD^{1,2}

Abstract

Integrated palliative care is viewed as having the potential to improve service coordination, efficiency, and quality outcomes for patients and family carers. However, the majority of Canadians do not have access to regional, comprehensive, integrated palliative care. Work needs to be directed toward planning palliative care services that is integrated into the healthcare and social care system. To further this goal, it is important to have a conceptual understanding of the meaning of integrated care and its expression in organizational models for the provision of palliative care.

Keywords: concepts; healthcare and social care; integrated care; organizational models; palliative care; taxonomy

THE LITERATURE HAS SHOWN that palliative care can have a positive impact on the quality of life of patients.^{1–6} However, the provision of palliative care is often still less than optimal.^{7,8} The majority of patients do not have access to the benefits of a regional, comprehensive, integrated palliative care program. Rather, patients are not always able to receive care in their preferred place of care, often transfer between sites of care, and experience unnecessary hospital admissions as they near the end of life. This report previews the literature on service integration and its implications for patient and family carer access to comprehensive and coordinated palliative care. For the purposes of this article, the World Health Organization's (WHO's) definition for integrated care will be employed describing integrated healthcare as "the organization and management of health services so that people get the care they need, when they need it, in ways that are user-friendly, achieve the desired results and provide value for money."⁹

Integrated care is viewed as an important framework to enhance quality of care, efficiency, and patient satisfaction in healthcare and social care systems.^{10–12} It is commonly viewed as an organizing principle for care delivery with the aim of achieving improved patient care through better coordination of services. However, despite the popularity of developing integrated models of care, the lack of a common language has hampered our understanding of its meaning. A recent review of the literature on integrated care revealed some 175 definitions and concepts.¹³ The diversity of definitions applied to integrated care has resulted in diverse approaches to integration, resulting in unequal access to palliative care.¹⁴

Moreover, integrated care means different things to different people, including patient, the healthcare provider, and

the health policy analyst.⁹ For the patient and family, integration of care means healthcare and social care that is seamlessly easy to navigate. Patients and their families want healthcare service that both minimizes the steps toward securing access to care and avoids redundancy. Having to repeat their story to care providers causes patients to feel as if the system is uninformed on their care needs. For healthcare providers, integration of care can mean that funding and provision of services and their support systems are coordinated. For the policy analyst, integration of care requires decompartmentalization of decisions on policies, financing, regulation, and delivery. Decentralization occurs when a network of public, private, and voluntary healthcare and social care services is brought together (as opposed to looking at the public sector in isolation).⁹

When considering the integrated care needs for the user, provider, and analyst, a range of strategies emerge in the literature that dictate how to develop an integrated care service model. The literature also coalesces into a common taxonomy that classifies the more common approaches on the application of integration of service models.^{12,15–17}

An organizing framework based on a taxonomy for the integration of care would play an important role in facilitating the description and comparison of different integrated service models that is useful for policy development, as well as implementation and evaluation of integrated service models. It is recognized in the literature that service integration is enabled through a range of processes that may focus on systems, teamwork, or professional behaviors. The types of integration are viewed as having interconnected roles on the system (macro), organizational (meso), and clinical (micro) levels^{17,18}:

¹School of Nursing and Midwifery, Queen's University Belfast, Belfast, United Kingdom.

²Department of Health Research Methods, Evidence, and Impact, McMaster University, Hamilton, Ontario, Canada.

Accepted November 20, 2017.

1. System. Coordinating and aligning policies, rules, and regulatory frameworks that promote horizontal and vertical integration (macro level).
2. Organizational. Interorganizational relationships, coordinating structures, and governance mechanisms to deliver comprehensive services to a defined population (meso level).
3. Administrative. Key support functions that include financial, management, and information systems structured around service delivery (micro, meso, and macro levels).
4. Clinical. The coordination of patient care across time, place, and discipline. This can include guidelines, care paths, interprofessional education, and multidisciplinary teamwork (micro level).
5. Normative. Developing shared values, culture, and vision across organizations, professional groups, and individuals (micro, meso, and macro levels).

There is a lack of evidence about what integrative types are best suited to a particular setting. The view is that the specific goals of the initiative for integrated care will shape what type of integration is suitable within a particular setting. Decisions about the type of service integration most relevant to a particular initiative will be guided by the goals of the project, stakeholders involved, existing arrangements, resources that are available, and the scale of the initiative.¹⁵

The extent of service integration witnessed in a particular initiative can also vary in intensity, ranging from full integration, involving the pooling of resources, through to the coordination of services wherein service delivery is provided by existing services that share clinical information and manage patient transition between services, through to service linkage that simply involves sharing clinical information between service organizations. It is now widely accepted that “one size of integrated care does not fit all.”^{12,15}

A number of factors have been identified in the literature as either facilitating or undermining efforts toward integrated care. These factors include the size and complexity of the change effort, presence of leadership from senior management, the presence of a supportive organizational culture, availability of information technology that supports data sharing, communication across healthcare and social care teams, and resources such as budgeting, adequate staffing, and a reasonable implementation timeline.^{12,15}

Integrated Care in Palliative Care

The WHO defines palliative care as an approach that improves the quality of life of patients and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment, and treatment of pain and other problems, physical, psychosocial, and spiritual.¹⁹

The WHO's definition of palliative care has implications on how the provision of palliative care is situated in a national health system.¹⁹ First, national health systems should include palliative care in the continuum of care linking it to prevention, early detection, and treatment programs. Palliative care services should also be provided alongside potential curative treatments and adapted to the needs of patient and families as the disease progresses. Integrating palliative care within regular treatment offered to patients with life-threatening disease is supported by a growing amount of evidence that demonstrates the effective-

ness of palliative care on the improvement of the quality of life of patients.¹⁻⁶ Second, palliative care services need to be provided in accordance with the principles of universal health coverage wherein all people should have access to palliative care services that are essential, safe, affordable, and effective.

The traditional focus on specialist palliative care teams caring for people with cancer in a hospital setting has been expanded to include a wide range of life-limiting disease groups and settings of care. Accompanying this expansion have been societal changes in living and social circumstances where traditional family caring roles cannot be taken for granted; individualistic and consumer choices have placed a greater demand on patients in determining and tailoring their healthcare, including the opportunity to be cared for and die in their place of preference. Given the increasing number and expanding profile of people with life-limiting illness, a population health approach to planning is required to inform the development of any model of palliative care that integrates with other services. Embedded in this approach is the acknowledgment that communities play an important role derived from possessing unique knowledge of their locality and thus most able to address disparities by recognizing the socioeconomic and geographic variables present in their locality as well as the relationships necessary for effective community development of integrated palliative care.²⁰

An obvious reference point toward articulating our understanding of what are the key elements of integrated palliative care can be traced back to the WHO definition of palliative care, which expresses the value of a holistic approach to care, recognizes both the patient and family as the unit of care, and the early application of palliative care in the course of the illness.¹⁹

In a European Commission funded project, InSUP-C (patient-centered integrated palliative care pathways in advanced cancer and chronic disease, 2012–2016; www.insup-c.eu), an international team of researchers have endeavored to identify the best way to deliver care to people at the end of life. Based on a consensus of the InSUP-C experts, their definition of integrated palliative care involves *bringing together administrative, organizational, clinical and service aspects in order to realize continuity of care between all actors involved in the care networks of patients receiving palliative care. It aims to achieve quality of life and well-supported dying process for the patient and the family in collaboration with all care givers (paid and unpaid).*²¹ One objective of the InSUP-C initiative, which merits attention in this report, has included identifying the requirements of promising practices for integration of palliative care in Europe.

An activity related to this objective was, through expert consensus, building a taxonomy for integrated palliative care applicable across diseases, healthcare sectors, and systems.²² Consisting of eight categories that include elements on service configuration, the taxonomy covers the process and structure of integrated palliative care initiatives.²² Categories range from the following:

1. Type of initiative: guidelines, pathway, and model.
2. Level of care: primary (general practitioner (GP), nursing service, and community care), secondary (specialist physicians, nurses, hospital, and inpatient hospice), and tertiary (cancer centers and academic training centers).
3. Sector: inpatient and homecare.

4. Time frame of intervention: early integration, concurrent, and end of life.
5. Focus of function: treating function, advising/consulting, and training.
6. Collaboration: network, protocols, team, and case management.
7. Key contact: GPs, nonpalliative care specialist, and palliative care specialist.

The taxonomy developed by the InSUP-C group represents a substantive step toward how we define and understand integrated palliative care. The complex character of the taxonomy reflects the wisdom that the expression of integrated palliative care is influenced by context or situation. Decisions about the type of integration, as stated earlier, are guided by project goals, stakeholders involved, existing arrangements, resources that are available, and the scale of the initiative.

Key learnings from the InSUP-C experience included recommendations on how to further integrate palliative care in Europe.²² These recommendations reinforced the notion that integrated care is about improving the care experience for patients and their families. Furthermore, organizational considerations should emphasize the importance on establishing formal structures and frameworks that promote care quality, communication, and smooth patient transition across settings. At the regional level one should stress the importance of integrated information systems that promote continuity of information across settings of care. Finally, at the health system level, accountability and evaluation mechanisms should be essential to measure and assess the impact of service integration on quality of care, user satisfaction, and effective organizational relationships.

Acknowledgments

The author acknowledged the contributions of the Palliative Care Matters Research Support Team: Sharna Polard and Roger Salus for library services and literature searching; Heather Styles and Michelle Sims for overall research coordination and assistance; and Viki Muller for literature screening, literature review, and project support.

Author Disclosure Statement

No competing financial interests exist.

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Address correspondence to:

Kevin Brazil, PhD
School of Nursing and Midwifery
Queen's University Belfast
97 Lisburn Road
Belfast BT7 7BL
United Kingdom

E-mail: k.brazil@qub.ac.uk