A Logic Model for End-of-Life and Palliative Care Services in Nova Scotia

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Executive Summary

Palliative care aims to relieve suffering and improve the quality of life for persons who are dying and their families. It addresses the physical, mental, emotional and spiritual wellbeing of these individuals and provides resources and supports accordingly. Yet, fragmented planning has meant that access to end-of-life and palliative care is often inadequate. This problem is expected to become exacerbated due to the fact that as the population ages, there will be an increasing demand for these services. As such, planning for end-of-life and palliative care programs throughout Nova Scotia will be vital.

The logic model is one method in which this planning can be addressed. It provides a method in which program planning, evaluation, implementation and communication can occur. It is based upon a stated goal, objective or purpose, and outlines the activities, outputs and outcomes which are associated accordingly. Logic models have recently been used in several areas of healthcare, and even within palliative care systems themselves.

In the proposed logic model, the stated objective is to ensure that all Nova Scotians have access to appropriate, quality end-of-life and palliative care services when and where they are needed through the appropriate and effective planning and delivery of these services. The proposed logic model includes the activities, outputs, outcomes and impacts which, if achieved, have the potential to effect change in end-of-life and palliative care in Nova Scotia.

Yet, further work is required to refine and validate the logic model. The limitations of the proposed logic model consist largely of the short project timeframe, the lack of broad stakeholder involvement in its development, and a lack of first-hand expertise in the content area. It is suggested that the proposed logic model be used as a starting point from which stakeholder consultation can occur to further the validation and refinement of the model. Subsequent to this, it is recommended that systematic outcome mapping and/or causal mapping be conducted to validate the model.

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Introduction

Context

Palliative care services have evolved rapidly since they were first provided in Canada in the 1970s (CHPCA, 2002). As a result of Canada's aging population, it is estimated that the demand for palliative care services will continue to increase over the next forty years (CHPCA, 2008). Yet, it has been reported that, in Canada, only 15% of individuals requiring palliative care services have access to them, and that this limited access is particularly pronounced in remote and rural areas (CHPCA, 2008).

In Nova Scotia, a province with many rural and remotes areas, all nine district health authorities (DHA) provide palliative care services for their respective adult populations and the IWK Health Centre provides palliative services for the children and youth across Nova Scotia. However, each DHA independently determines how to provide these services. Although each DHA is best able to recognize and adapt to the needs of its population, and make resource allocation decisions accordingly, the result of this is a variation in how palliative care services are provided throughout the province. Similar to the rest of Canada, this variability in palliative care services in Nova Scotia has been attributed to a lack of comprehensive and standardized programs (CHPCA, 2002). As such, it is possible that program planning and evaluation may be useful in addressing these disparities. The logic model is one method in which such planning may be accomplished. Moreover, the use of a logic model can also aid in the evaluation of the various approaches across the province. Thus, this paper attempts to provide the foundation for the development of a logic model for end-of-life and palliative care in Nova Scotia.

History

Hospice palliative care originated in Canada in the 1970's when cancer treatment programs were expanded to be either curative or palliative (CHPCA, 2009). In the decades since that time, palliative care has expanded and evolved. However, this evolution has developed in the absence of national or provincial directions, with individual hospitals and cities throughout the country designating palliative care beds and planning services independently (CHPCA, 2009). As such, several federal reports have identified the fragmented approach to planning as a barrier for some individuals, particularly in rural areas, in accessing palliative and end-of-life services (Carstairs, 2000; Kirby, 2002; Romanow, 2002).

This "variable and fragmented nature of hospice palliative care services across Canada" has been a reality in Nova Scotia as well (Government of Nova Scotia, 2005, p. 1). The province has been witness to the development of hospice palliative care services unevenly throughout districts and care settings (Government of Nova Scotia, 2005). In response, the province produced the *Provincial Hospice Palliative Care Project (PHPCP)*, in which it outlined a provincial approach to hospice palliative care (Government of Nova Scotia, 2005). The values and principles identified in this report were used to guide the development of the logic model (see Appendix B).

Definitions

There is a wide range of terms which are used within the field of end-of-life and palliative care. Although many of these terms are often used interchangeably, there are distinctions pertaining to each term which necessitate clarification on the differences between them (see Appendix A - Glossary).

Palliative care (or hospice palliative care) is an end of life service which aims to relieve "suffering and/or improves the quality of living and/or dying for those individuals who are living with a progressive life-threatening illness/injury at the end of life and/or who are bereaved" (Government of Nova Scotia, 2005, p. 1). More specifically, it is a "combination of active and compassionate therapies that address the physical, psychological, social, spiritual and practical needs of individuals who are living with a life threatening illness and their families" (Government of Nova Scotia, 2005, p. 1). Palliative care not only addresses these needs, but also prepares the individual (and family) for the ability to self-manage the dying process and cope with loss and grief during the illness and bereavement periods (NSHPCA, 2009). As such, palliative care is "appropriate for any patient and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care" (NSHPCA, 2009).

Logic Models

Logic models have been used since the 1980s, and were first introduced to aid in the identification of essential program activities, to outline appropriate outcomes, and to suggest plausible theories for how the activities and anticipated outcomes were associated (Gugiu & Rodriguez-Campos, 2007). Today, logic models are used in program planning, evaluation and implementation (W.K. Kellogg Foundation, 2004). In essence, logic models are "representations of the relationship between program activities and their intended effects and are used for both program planning and evaluation" (Sitaker, Jernigan, Ladd, & Patanian, 2008, p. 1).

Alternatively, they have been described as a "flexible, multiuse framework for thoroughly defining" a program and/or for conducting evaluation (Morzinski & Montagnini, 2002, p. 567).

As indicted, the logic model can serve several purposes. First, it may be used for program planning. As such, it assists in the development of the program through a strategic process. Secondly, it may be used for program management, in that it makes associations between the resources, activities and outcomes. Additionally, the logic model may be used for evaluation because it can help track and monitor more efficiently and effectively. Alternatively, the logic model may be used as a tool for communication to report on the outcomes of the activities. Lastly, the logic model can be used for consensus-building, as it builds a common understanding among stakeholders regarding what exactly the program entails (Innovation Network, 2008). Overall, this is best summarized in that

> The purpose of a logic model is to provide stakeholders with a road map describing the sequence of related events connecting the need for the planned program with the program's desired results. Mapping a proposed program helps [to] visualize and understand how human and financial investments can contribute to achieving [the] intended program goals and can lead to program improvements (W.K. Kellogg Foundation, 2004, p. 3).

In essence, every program is based on an implicit or explicit "'theory of change' – a theory about how and why the program will work" (Innovation Network, 2008, p. 2). The logic model is a representation of how this theory connects the program's goals with its activities. In other words, the logic model "shows the relationships between what is put into the program

(resources), what the program does (activities and outputs), and what results (outcomes) the program produces" (Innovation Network, 2008, p. 2).

The value in logic models is best articulated by Gugiu and Rodriguez-Campos (2007) who, in recognition of the fact that program planning and evaluation is challenging and time-consuming, state that:

> Without a well-defined model to guide the evaluation design, program managers run the risk of implementing an evaluation plan that does not focus on the most salient dimensions of the program (e.g. activities, outcomes, etc.) and thus, may develop and implement a poor evaluation strategy (p.339).

In response, the logic model may be used to avoid such pitfalls owing to the fact that it takes into consideration the activities and outcomes to which the program aspires. Moreover, designing a logic model can enable stakeholders to: articulate what will be done, as well as why and how it will be done; identify gaps within the process; produce a common framework which can be used by all stakeholders; set realistic expectations; and learn about the program itself (Innovation Network, 2008).

From a practical perspective, the logic model can be used at any point in the life of a program – either in design, reflection on redesign, evaluation, implementation, or for reporting on outcomes (Morzinski & Montagnini, 2002). Moreover, it can be used in either direction (either starting with the activities and working toward the outcomes, or starting with the outcomes and subsequently determining the activities) (Morzinski & Montagnini, 2002). In addition, there are three different forms of the logic model: the Theory Approach Model; the Outcomes Approach Model; and the Activities Approach Model (W.K. Kellogg Foundation,

2004). While each of these forms is slightly different, all three include the same elements of the logic model: activities, outputs, impacts and outcomes.

The first of three models is the Theory Approach Model which focuses on the theory of change which was the impetus for designing and planning the program (W.K. Kellogg Foundation, 2004). As such, this approach is most useful for program planning, emphasizes the theoretical premises upon which the program is based, and often proceeds by identifying activities which have been linked to proven strategies (W.K. Kellogg Foundation, 2004). Similarly, the second model is the Activities Approach Model which is predominantly used for implementing logic models (W.K. Kellogg Foundation, 2004). As such, it links the proposed activities together in order to map the implementation process, emphasizes the intention of the program, and details exactly what the program will do through its activities (W.K. Kellogg Foundation, 2004)

Of the three forms of logic models, the third approach, the Outcomes Approach Model, is the form which is applied for end-of-life and palliative care services in Nova Scotia. This model emphasizes the attempt to connect the activities with the intended results in a workable program. Unlike the other two approaches, this model is also the most appropriate for evaluation, does not focus too intently on the specific details within a program and/or process, and does not attempt to explain underlying assumptions behind program. Furthermore, it has been suggested that by determining the outcomes first, it is better able to predict the success of those outcomes (Government of Nova Scotia, 2005). Thus, while the logic model is explained from activities through to outcomes, the outcomes themselves informed the activities.

Logic Modelling and Palliative Care

In addition to increasingly being used for grant proposals, logic models have successfully been used for programs within healthcare (Sitaker et al., 2008). Yet, from a search of the literature using databases such as PubMed, and through a broader search using Google, only two reports of the use of logic models being applied to palliative care programs were found. Morzinski and Montagnini (2002) outline the use of a logic model as a framework for designing and monitoring a Palliative Care Educational Program in the United States. In Canada, the Calgary Health Region has used a logic model for their Care at the End of Life Initiative. Although the purposes of this logic model were much narrower in scope, this logic model serves as an example of how a logic model can be applied to end-of-life and palliative care.

The first step in developing a logic model is the identification of the problem or purpose to which the logic model will speak. However, this may not be intuitive due to the fact that end-of-life services and palliative care are continuously evolving. Yet, it is necessary to ensure that this evolution is appropriate and that the desired objectives are being met. Provincial planning must account for this order to provide optimal quality services to Nova Scotians. One of the main goals of palliative care programs is that "ultimately, it is hoped that instead of being seen as 'care for the dying,' hospice palliative care will be known as 'care that aims to relieve suffering and improve quality of life throughout the illness and bereavement experience, so that patients and families can realize their full potential to live even when they are dying' (CHPCA, 2002, p. v). This goal should be held paramount in determining the objective and/or purpose of any logic model. Therefore, the objective of this logic model is to provide an overview of end-of-life and palliative care in Nova Scotia for planning and evaluation, so that all Nova Scotians needing end-

of-life and palliative care have timely access to these services when and where they are needed and/or desired.

Once the objective or purpose of the logic model is identified, the model can be designed as previously described. The end-of-life and palliative care logic model was adapted from a previous logic model created for primary care services in Nova Scotia (Pyra Management Consulting Services Inc., 2006). Upon adapting this model, the end-of-life and palliative care logic model was built upon using an outcomes-up approach. As such, consultation with key informants, including those from the Network for End-of-Life Studies (NELS) Interdisciplinary Capacity Enhancement (ICE), allowed for the identification of desired outcomes, which then gave rise to the outputs and activities which would be necessary to produce those outcomes. Accordingly, this logic model for end-of-life and palliative care is displayed in Table 1. It should be noted, however, that the list of activities, outputs, outcomes and impacts are not listed in order of importance. As this logic model is intended to be the foundation for further work, it was beyond the scope of this paper to assign value to each of these components.

Logic Model Design and Components

Components	Elements
Activities	1. Population-based planning 2. Funding 3. Partnership development and collaboration among health professionals and among organizations 4. Networking, coordination, and knowledge translation among health professionals and among organizations 5. Evaluation and research 6. Service development, best practices and capacity building 7. Policy development and advocacy 8. Change management, training and education 9. Communication and awareness-building 10. Implementing and using information technology
Outputs	1. Planning for service delivery is informed by evidence and focused on meeting the needs of the person at end of life and his/her family and/or support system 2. Accountabilities within relationships (DHAs/DoH) in the Palliative Care/End of Life health care system are clearly defined 3. Quality services are delivered in a coordinated way 4. A sufficient range of services and programs are provided to enable choices 5. Healthcare providers collaborate 6. Healthcare providers' knowledge, skills and attitudes are appropriate to the services provided 7. Individuals who have had experience with end-of-life and palliative care, health providers and communities have capacity to participate in planning and delivery 8. Services are offered in ways that respond to individuals', families' and communities' cultural, racial and spiritual needs
Outcomes	1. Population-level health and wellness are improved through the lens of a good death and quaternary prevention 2. Inequities in access to end-of-life and palliative care among Nova Scotians are being addressed 3. All aspects of end-of-life and palliative care planning and delivery throughout the province are accountable, sustainable, and integrated 4. Persons and families are satisfied with, and feel supported through, the end of life and bereavement processes
Impacts	1. Individuals, families, and all care providers have access to information on optimal end of life care and performance data 2. Individuals and families experience continuity of care 3. The formal (paid) and informal (volunteer) healthcare providers are supported, healthy, and feel a sense of purpose and being valued 4. Quality end of life and palliative care services are efficient, effective, affordable and acceptable 5. Society and individuals accept death as a meaningful part of life and work together to provide optimum end of life care given evidence and community norms

Table 1. Logic model for end-of-life and palliative care services in Nova Scotia (as adapted from the Primary Health Care System Logic Model, 2006).

Activities

The program's activities consist of what the program does with its resources (human and financial), and may include the processes, tools, events, technology and/or actions which are an intentional part of the program design and implementation, and are used to bring about the intended change and/or results (W.K. Kellogg Foundation, 2004). The activities included in the end-of-life and palliative care logic model are as follows:

1. Population-based planning

To overcome the fragmented provision of palliative care services throughout the province, population-based planning at the provincial level is advised. Care should be integrated across the continuums of care in each health district and the IWK. In other words, individuals requiring end-of-life and palliative care should be able to access these services regardless of their location within the province. This integration of care across continuums includes ensuring that access to services is equitable across the province, and that the transition between services is seamless. Nova Scotia's government, itself, has stated that priorities must be assessed from a provincial perspective especially due to the potential for federal cost-sharing opportunities (Government of Nova Scotia, 2005).

2. Funding

It has been reported that due to healthcare restructuring throughout Canada, institutional-based palliative care funding has been cut under the premise that care would be devolved to community-based organizations (CHPCA, 2008) . Yet, the funding of such community-based programs has not increased proportionately, and this has left a gap in the healthcare system

(CHPCA, 2008). As Nova Scotia's population ages, it is expected that palliative care services will increase in demand (NELS ICE, 2008). As such, it is necessary that adequate resources are provided throughout the province to ensure that end-of-life and palliative care services and programs can meet this demand.

The Canadian Hospice Palliative Care Association (CHPCA) states that funding is currently inadequate, and should be increased, for many of the other activities within this logic model, including research, education and training (CHPCA, 2008). Furthermore, they also contend that it is not acceptable that end-of-life and palliative care services/programs should have to depend upon charitable donations to the extent which they do currently (CHPCA, 2008).

3. *Partnership development and collaboration among health professionals and among*
   organizations

It has been argued that interdisciplinary collaboration is essential in the delivery of quality (as defined as a guiding principle in Appendix B) end-of-life and palliative care (Hall & Weaver, 2001). This is supported by the Nova Scotia Hospice Palliative Care Association, who has stated that "hospice palliative care is most effectively delivered by an interdisciplinary team of health care providers who are both knowledgeable and skilled in all aspects of the caring process related to their discipline or practice" (NSHPCA, 2009).

4. *Networking, integration, coordination, and knowledge translation among the DHAs*
   (coordinated through the DoH)

The importance of knowledge translation in healthcare, and its relevance in this logic model, is best articulated through its definition as the "exchange, synthesis and ethically sound application of knowledge – within a complex system of interactions among researchers and users

– to accelerate the capture of the benefits of research ... through improved health, more effective services and products, and a strengthened health care system" (Davis, et al., 2003, p. 33). As such, district health authorities (DHAs) must work with each other and the Department of Health (DoH) to share information. Activities such as benchmarking require this type of sharing of information. Likewise, areas of success should be identified and that knowledge should be translated so that other areas may share in that success

In addition, the DHAs must work collaboratively to determine the optimal method in which end-of-life and palliative care services can be delivered. Program planning is a district health authority activity, and as such, it is up to these authorities to plan for their own constituents while recognizing that they function within a larger system. While recognizing the inherent differences among the health authorities, investigations to determine how these services can be provided equitably throughout the province in a more consistent manner may further this work.

5. Evaluation and research

Research is one of the guiding principles taken from the *PHPCP* (see Appendix B). As a guiding principle, it outlines that "the development, dissemination and integration of new knowledge is critical" and that all activities should be "based on the best available evidence" (Government of Nova Scotia, 2005, p. 6). Taken together, this outlines that this activity must include the development of new knowledge, the synthesis and integration of that knowledge, and the dissemination of that knowledge so that activities are based on best evidence. Without the proper data collection and assessment (evaluation), it is difficult to determine that appropriate services are being delivered when and where they are needed. The Carstairs Report has

suggested that a component of this activity should include the development of relevant indicators for quality end-of-life care (Carstairs, 2005).

Specifically, the CHPCA has recommended that a sustained hospice palliative care research strategy is necessary to ascertain that there is a coordinated approach on this issue (CHPCA, 2008). They further contend that one example of this may entail building research capacity within the system by establishing more fellowships in end-of-life and hospice palliative care areas (CHPCA, 2008).

6. *Service development, best practices and capacity building*

The development of quality end-of-life and palliative care services must be based on identified best practices within this field which allow for growth and enhanced ability to respond to changes and challenges as the service develops. Appropriate, quality services (as defined in the second guiding principle of Appendix B) can only be delivered if they can first be identified. The NHS' *Gold Standards Framework* identifies three processes in developing best practice: i) identifying individuals in need of palliative care towards the end of life; ii) assessing their needs, symptoms, preferences and important issues; and iii) planning care around the patients' needs and preferences (Thomas, 2005).

7. *Policy development and advocacy*

A key component in the development of policy and advocacy is stakeholder involvement. This is based on the eighth guiding principle (see Appendix B) which calls for advocacy-based activities which include interactions with stakeholders such as "legislators, regulators, policy makers, healthcare funders, other hospice palliative care providers, professional societies and associations, and the public" (Government of Nova Scotia, 2005, p. 6). Importantly, the CHPCA

notes that the role of informal and family caregivers has been increasing in recent times, and it is

these individuals who can best identify the supports and resources which are necessary in this

area (CHPCA, 2008).

Activities involving policy development and advocacy are numerous, diverse, and must

be completed for all aspects of end-of-life and palliative care services/programs. One such

example includes devising policy to incent physicians to practice palliative care in the

community (as the province remunerates physicians based on clinical procedures, none of which

include palliative care within their purview) (CHPCA, 2008). Similarly, policy is necessary to

address the burden which informal and family caregivers may experience within end-of-life care.

Additional supports are necessary for these individuals during this time, and they are a resource

which the healthcare system cannot afford to lose.

It should be noted that there are several policy-related recommendations in this area

which currently exist. For example, the *Continuing Care Strategy for Nova Scotia* contains a

recommendation for the development of a provincial palliative care program which includes

"home care authorizations, oxygen, and medication coverage [which] will mean that families

will have more choices when a loved one is faced with a life-threatening illness" (Nova Scotia

Department of Health, 2006, p. 7). Promisingly, work in this area has been initiated, some

successes have been realized, and further work is planned (Nova Scotia Department of Health,

2008).

Likewise, it is necessary that end-of-life and palliative care services/programs collaborate

with advocacy groups who specialize in related areas. For example, the Nova Scotia Hospice

Palliative Care Association and the Canadian Hospice Palliative Care Association are two

important groups with ample knowledge who are willing and able to advocate for many of the

issues pertaining to this area of healthcare.

8. *Change management, training and education*

As with any change, stakeholders should be guided through the process through training

and education. It has been reported that transformational change efforts often fail due to a lack

of education of stakeholders through communication (Kotter, 1995). Similarly, it has been

reported that change management is a complex process which requires effective communication

to successful navigate (Lozon & MacGilchrist, 1999). As such, it can be deduced that education

and training of stakeholders, through the use of effective communication are key activities for

change management. Again, this activity can be related to others, and its impetus expressed

through its application to other initiatives within Nova Scotia. This is best exemplified in the

Continuing Care Strategy for Nova Scotia which states that

> Change must be fundamental – new learning must lead to new ways of thinking, and new
>
> capacity in the system. Governments and organizations must find new ways of building
>
> capacity within the system. Decisions will need to be based on evidence, and funding
>
> must be sustainable (Nova Scotia Department of Health, 2006, p. 15).

Furthermore, the Carstairs Report states that education is a key component to ensure that

Canadians receive quality palliative care services, and that this education is best delivered in an

interdisciplinary approach (including physicians, nurses, pharmacists, physiotherapists, social

workers and spiritual advisors) (Carstairs, 2005). Moreover, education activities are paramount

to training healthcare professionals for palliative care. For example, there are only just over 200

palliative care physicians in Canada. As such, the CHPCA contends that many of the palliative

care services are provided by family physicians that often lack adequate training in pain

management and other palliative care related skills (CHPCA, 2008).

9. Communication and awareness-building

Communication is a key activity, and a component of each other activity within the

model. Effective communication is necessary among all stakeholders: between the Department

of Health and the health authorities; between the interdisciplinary healthcare professionals;

between healthcare professionals and individuals and their families.

The other piece of this activity involves raising awareness among the public regarding the

programs and services which are available for them, and for which their input is sought. The

CHPCA contends that by communicating the gaps in service which currently exist, the public

can become an ally in the attempt to address these issues (CHPCA, 2008).

10. Implementing and using information technology

Information technology is necessary to facilitate research, communication, and the delivery

of patient care. For example, it has been recommended that information technology is necessary

not only to support service delivery and evaluation, but also for the monitoring of program

indicators themselves (Government of Nova Scotia, 2005).

Outputs

The outputs are the direct products of the activities (W.K. Kellogg Foundation, 2004).

They are measurable and tangible, and can help in the assessment of how well the program is

being implemented (Innovation Network, 2008). If the outputs occur appropriately, then it can

be expected that the intended outcomes will also occur (Morzinski & Montagnini, 2002).

Moreover, unlike outcomes, stakeholders should have greater direct control over the outputs

(Government of Canada, 1993). The logic model for end-of-life and palliative care in Nova

Scotia, as adapted from the primary health care logic model and informed through consultation

with stakeholders, suggests that these outputs include:

1. *Planning for service delivery is informed by evidence and focused on meeting the needs of*

   the person at end of life and his/her family and/or support system

   This output is proposed to result from activities involving: provincial/population-based

planning; service development; evaluation and research; and stakeholder involvement. Success

in this area may be determined by the number and extent of initiatives, services, policies and

decisions developed based on well-founded evidence.

2. *Accountabilities within relationships (DHAs/DoH) in the Palliative Care/End of Life health*

   care system are clearly defined

   This output may result from activities involving: knowledge translation and information

sharing; networking and co-ordination among the district health authorities; and policy

development. Success may be measured by satisfaction surveys among those in reporting

relationships within the system and/or evidence of clearly developed and disseminated

accountability contracts (i.e. written accountabilities which have been acknowledged by all

relevant parties).

3. *Quality services and programs are delivered in a coordinated way*

   This output stems from activities related to: provincial/population-based planning;

funding; partnership development; the dissemination/sharing of information; and the networking

and collaboration among district health authorities. Its success may be measured by satisfaction

surveys (staff and individuals/families), quality of life indicators, and quality of care indicators.

4. *A sufficient range of services and programs are provided to enable choices*

This output relates to activities pertaining to: stakeholder involvement; service

development; and communication and increased awareness. Success in this area may best be

measured through individual/family and caregiver satisfaction surveys.

5. *Healthcare providers collaborate*

This output may result from activities related to: partnership development; change

management and education/training; and service development and best practice. Although there

are various indicators and measures of success in this area, many are challenging. Satisfaction

surveys completed by providers may be useful, but not sufficient to measure success in this area.

As such, further structural measures are necessary to garner a more complete evaluation. These

may include indicators related to interdisciplinary practices, education, and participation.

6. *Healthcare providers' knowledge, skills and attitudes are appropriate to the services*

    provided

This output stems from activities related to: change management, education and training;

and communication. Again, a satisfaction survey may be used as a measure of success in this

area, relevant to provider attitudes, but would not be sufficient to measure a change in

knowledge and skills. Measures related to knowledge and skills may relate to adherence to

criteria such as best practice guidelines.

7. *Individuals, health providers and communities have capacity to participate in planning and*

    delivery

This output may result from activities related to: stakeholder involvement; partnership development; and networking and collaboration. Success in this area may be measurable by changes in the extent of stakeholder participation in planning, the number of community meetings which occur, the extent of implementation of self-care, and the percentage of families who receive follow-up from a social worker and/or bereavement coordinator.

8. *Services are offered in ways that respond to individuals', families', and communities' cultural, racial and spiritual needs*

This output is related to activities including: stakeholder involvement; service development; and communication, education and training. Success in this area may be measured by individual/family and caregiver satisfaction surveys. In addition, measures might include the number of referrals received for these services, and a measure of timeliness for these referrals.

Outcomes

The outcomes are the achievements and changes which occur in the program participants' behaviour, knowledge, skills, status and level of functioning as a result of the activities (W.K. Kellogg Foundation, 2004). Ultimately, the outcomes are not directly controllable. Unlike outputs, the outcome can only be influenced by stakeholders (Government of Canada, 1993). Overall, outcomes express the results which the program aims to achieve (Innovation Network, 2008). This logic model was constructed "from the outcomes up". Thus, the outcomes were established first, through consultation with key informants, and subsequently informed the activities and outputs. The outcomes in this logic model are related to the stated goal/objective/purpose and include:

1. *Population-level health and wellness are improved through the lens of a good death and quaternary prevention*

2. *Inequities in access to end-of-life and palliative care among Nova Scotians are being addressed*

3. *All aspects of end-of-life and palliative care planning and delivery are accountable, sustainable, and integrated*

4. *Individuals and families are satisfied with, and feel supported through, the end of life and bereavement processes*

Impacts

While the other three components are common to all logic models, the impacts may or may not be included in the model. The impact refers to "the fundamental intended or unintended change occurring in organizations, communities or systems as a result of program activities" (W.K. Kellogg Foundation, 2004, p. 2). In this case the impacts include:

1. *Individuals, families, and all care providers have access to information on optimal end of life care, services, programs, and performance data*

2. *Individuals and families experience continuity of care*

3. *The formal (paid) and informal (volunteer) healthcare providers are supported, healthy, and feel a sense of purpose and being valued*

4. *Quality end of life and palliative care services are efficient, effective, affordable and acceptable*

5. *Society and individuals accept death as a meaningful part of life and work together to provide optimum end of life care given evidence and community norms*

Assumptions, Risks and Limitations

Logic models, by their nature, are based upon assumptions; and every assumption carries a certain amount of risk. For example, it is inherently assumed (although supported by evidence) that change is necessary within the end-of-life and palliative care system and programs. Moreover, it is assumed that the theory of change upon which the logic model is based will not only lead to change, but also to positive change. It is assumed that the change is possible, and that the activities are related to the outcomes. Likewise, it is assumed that there are resources available to implement the changes. However, the risk of errors in these assumptions are common to all logic models, and do not necessarily negate the value of them.

In addition, there are several limitations to this logic model. The first relates to the fact that wide stakeholder input and involvement did not occur in the initial stages of development of the model. It is recommended that a wide representation of stakeholders be involved in the design and development of the logic model (Innovation Network, 2008; W.K. Kellogg Foundation, 2004). Specifically, it has been said that "most of the value in a logic model is in the process of creating, validating, and modifying the model ... the clarity of thinking which occurs from building the model is critical to the overall success of the program" (W.K. Kellogg Foundation, 2004, p. 2). The development of the end-of-life and palliative care logic model was based on reports on end-of-life and palliative care, in conjunction with discussions with a limited number of strategic informants. This work is intended to be a base for broader stakeholder discussion and input. Critiques, adaptations, and revisions of the logic model are key steps in the process toward a consensus on a valid model.

Secondly, a limitation is that this logic model does not elaborate on the available factors (barriers and/or resources) which may impact the effectiveness of the program. Although these

factors are not necessarily included in every logic model, their inclusion can remove one of the main related assumptions and slightly increase certainty in the model. Thirdly, while logic models reflect a seemingly linear relationship between activities and outcomes, in actuality, the programs are much more complex and diverse than they appear within the model (Innovation Network, 2008). Moreover, this complexity can pose further challenges because the logic model does not include a "feedback" mechanism. In other words, if the desired outcomes are not achieved, the model does not provide direction on where the error occurred within the model or areas which may be altered to achieve the desired outcomes.

A further limitation consists of the challenge in identifying measures and indicators for the evaluation of the logic model through measures of output success. This was due, in part, to the limited timeframe in which this model was developed. This limitation would likely be corrected through broader stakeholder consultation.

Finally, a limitation in all logic models is the fact that programs are not static and therefore, the components within the model must be ever-evolving. This is best articulated by the W.K. Kellogg Foundation paper (2004) which states that:

> As a program grows and develops, so does its logic model. A program logic model is merely a snapshot of a program at one point in time; it is not the program with the actual flow of events and outcomes. A logic model is a work in progress, a working draft that can be refined as the program develops (p.7).

This is considered of the utmost importance when the program goals, themselves, change (Morzinski & Montagnini, 2002). In such circumstances, it is necessary to re-evaluate the activities and outcomes to ensure that they are aligned with the program goals. This is not an

easy task, considering the temporal resources which are required to produce the logic model itself. However, the absence of a logic model is a greater challenge to the effective design, evaluation and implementation of such programs.

Future Directions

The next step in this logic model development process would be the review, refinement and validation of the model by stakeholders to ensure that the stated goal, activities and outcomes are appropriate. One form of validation of this logic model is systematic outcome mapping or causal mapping (Persaud & Nestman, 2006; Scavarda, Bouzdine-Chameeva, Goldstein, Hays, & Hill, 2004). This is achieved through establishing linkages between the activities and their outcomes, and using feedback from indicators (such as those used for the outputs) to modify those activities. Although causal mapping is labour intensive, it can produce a better quality logic model.

Conclusion

The realities currently existing within end-of-life and palliative care services in Nova Scotia, coupled with the expected increase in demand for such services, require further program planning. This planning may be aided by the development of a logic model, with the objective of ensuring that all Nova Scotians have access to appropriate, quality services when and where they needed through the appropriate planning and delivery of those services. It has been stated that

Logic modeling's key contribution is that it enables program staff to illuminate logical,

sequential links between needs, program elements and outcomes, to guide program

revisions and to organize data collection to support program continuation or expansion

(Morzinski & Montagnini, 2002, p. 567).

Overall, it seems appropriate to apply a logic model to end-of-life and palliative care in Nova

Scotia. It is hoped that the proposed logic model may assist in achieving the stated objectives.

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Appendix A - Glossary

End-of-life Care:

"Care that helps all those with advanced progressive incurable illness to live as well as possible until they die" (Murray, 2005). This includes all illnesses; and patients living with the condition may die within weeks, months or years (Murray, 2005).

Supportive Care:

Care which focuses on assisting the patient and family cope with the illness; although it is not disease or time specific (Murray, 2005).

Palliative Care:

The holistic care of individuals, which includes the physical, psychological, social and spiritual care; it may be provided concurrently with curative treatment (Murray, 2005).

Terminal Care:

Upon being diagnosed as dying, it is the care which is provided in the last hours and/or days of life (Murray, 2005).
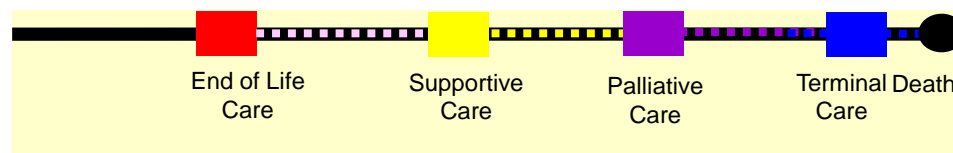

Figure 1. Association between terms and definitions as provided in *The Gold Standards Framework for End-of-life Care in the Community* (Murray, 2005).

Appendix B – Values & Guiding Principles from the Provincial Hospice Palliative Care Project

Values:

Hospice palliative care is based on and ***continuously supported*** by the following values:

- The central and unique value of each and every person. This includes those who are independent and able to make decisions for themselves as well as infants, children, and cognitively impaired adults who may require someone else to act on their behalf.
- The value of life, the natural process of death, and the fact that both provide opportunities for personal growth and self-actualization.
- The need to address individuals' and families suffering, expectations, needs, hopes and fears.
- Care is only provided when the individual and/or family is prepared to accept it.
- Care is guided by quality of life as defined by the individual.
- Caregivers enter into a therapeutic relationship with individuals and families based on dignity and integrity.
- A unified response to suffering strengthens communities

Guiding Principles:

The following principles are essential to and ***continuously guide*** the development and delivery of hospice palliative care services:

1. Individual and Family Focussed

As individuals are typically part of a family, when care is provided the individual and family are treated as a unit. All aspects of care are provided in a manner that is sensitive to the individual and family's personal, cultural, and religious values, beliefs and practices, their developmental state and preparedness to deal with the dying process.

2. High Quality

All hospice palliative care activities are guided by:
- the ethical principles of autonomy, beneficence, non-maleficence, justice, truthtelling and confidentiality.
- policies, procedures, and care processes that are based on the best available evidence or opinion-based preferred practice guidelines
- data collection / documentation guidelines that are based on validated measurement tools.

3. Safe and Effective

All hospice palliative care activities are conducted in a manner that:
• is interdisciplinary and team-based
• is collaborative
• ensures confidentiality and privacy
• is without coercion, discrimination, harassment or prejudice
• ensures safety and security for all participants
• ensures continuity and accountability
• aims to minimize unnecessary duplication and repetition
• complies with laws, regulations and policies in effect within the jurisdiction, host and hospice palliative care organization.

4. Accessible
All individuals and families have equal access to hospice palliative care services:
• as they choose and at an easily accessed point of entry
• wherever they live and /or choose to receive services, recognizing that creative efforts are required to overcome geographic isolation.
• in a timely manner as identified by the service delivery organization

5. Adequately Resourced
Resources are allocated based on the DHA's capabilities and priorities. The financial, human, information, physical and community resources are sufficient to sustain the program activities, as determined in strategic and business plans.

6. Collaborative
Each community's needs for hospice palliative care are assessed and addressed through the collaborative efforts of available organizations and services in partnership with the District Health Authority.

7. Knowledge-Based
Ongoing education of all individuals, families, caregivers, staff and stakeholders is integral to the provision and advancement of quality hospice palliative care.

8. Advocacy-Based
Regular interaction with legislators, regulators, policy makers, healthcare funders, other hospice palliative care providers, professional societies and associations, and the public is essential to increase awareness about, and develop, hospice palliative care activities and the resources that support them. All advocacy recognizes the Canadian Hospice Palliative Care Association's *A Model to Guide Hospice Palliative Care*. (Ottawa, 2002). The work of this project is based on that document.

9. Research-Based
The development, dissemination, and integration of new knowledge is critical to the advancement of quality hospice palliative care. Where possible, all activities are based on the best available evidence. All research protocols comply with legislation and regulations governing research and the involvement of human subjects in effect within the jurisdiction.

Source: Provincial Hospice Palliative Care Project (Government of Nova Scotia, 2005)