

PROJECT REPORT



*The Rurban
Hospice Palliative
Care Project*

*Final Report
April 27, 2006*

Pallium Project (Phase II) introductory note – The Pallium Project has mounted this sub-project Final Report as submitted by the Regina Qu'Appelle Health Region.

The Rurban Hospice Palliative Care Project Acknowledgements



The Rurban Project team wishes to acknowledge all those who contributed so generously of their time, energy, expertise and passion for ensuring accessible, quality end of life care. Thank you to the physicians, health care providers, RQHR and Palliative Care staff, the Pallium Project, volunteers, community members, family member, the Advisory and Steering Committees and the consultant team.

The Rurban Project was jointly championed and funded by the Regina Qu'Appelle Health Region and the Pallium Project (Phase II). This report is being made available to all those who participated in the project and to other jurisdictions and health authorities across Western Canada.

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Executive Summary

The need for quality end of life care in Canada is growing as the population ages and attitudes shift. The Rurban Hospice Palliative Care Project, undertaken by Regina Qu'Appelle Health Region in partnership with the Pallium Project, set out to develop a model for providing quality hospice palliative care across the rural and urban areas within a health region. Briefly stated:

Rurban is a term coined to describe an approach where hospice palliative and end of life care services within a Regional Health Authority are organized to deliver comprehensive, consistent, and accessible care throughout the region.

The **purpose** of the project was to develop a primary health care approach for hospice palliative care.

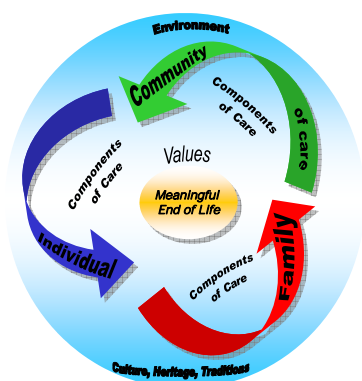
The **intended outcomes** were:

- A **flexible, sustainable model** for providing hospice palliative care
- A **process road map** to guide regional authorities in adapting the model
- **Strengthened community** relationships, confidence and ownership
- Test **application** of the model in the Regina Qu'Appelle Health Region.

The project methodology was action research based. It drew extensively from community development and capacity building theory, strength based approaches i.e. appreciative inquiry and systems thinking.

A series of half-day community consultations was held in addition to meetings with First Nations, rural physicians, researchers and a larger stakeholder group. Interviews were conducted with seven families, resources gathered on current best practices and an interactive web site established.

The Rurban Model that emerged illustrates an approach for engaging communities in the development and/or enhancement of their hospice palliative care services.



The patient's experience of a *meaningful end of life* is placed at the center as the focal point. The Dimensions, Family Individual and Community of Care, denote those who participate in the end of life care – both in contributing to and receiving care. The arrows illustrate the flow between the Dimensions.

The Components of Care identify the conditions that support a *meaningful end of life*. The blue shaded area represents the Environment - the values, culture, traditions, geography, unique characteristics and specific requirements of the region.

The road map of the development process, from initial introduction of the Rurban Model as a *strategic initiative*, to an established operational program within a regional health authority, involves three phases over approximately a 2-3 year period.

Phase I has been completed in RQHR, as the test site. The community response was overwhelming - community sessions involving practitioners, volunteers and community members were filled to capacity, family members generously shared their experiences during the private interviews, and the rural physicians spoke candidly of what brings a deep sense of meaning to their work with palliative patients and of the supports they require as care givers. The findings and recommendations gleaned from the experience to date are as follows:

Key Findings:

1. The response reaffirmed the importance of meaningful community involvement. It also recognized that community-based collaboration and focused capacity building do, however, require time, resources, skill and the commitment to foster relationships and to ensure all the key stakeholders are brought to the table at the onset.
2. How the project is framed makes a world of difference! The focus of the discussions and research was on a *meaningful end of life*, firmly placing the patient at the center of the development process. This, in addition to the use of an appreciative approach, helped to create a sense of ownership and confidence.
3. The Rurban Model denotes a shift in how palliative care is developed and delivered across the rural and urban areas of a health region. Leadership is crucial requiring a project leader with the skills and resources to guide the project, community leaders and champions and the shared leadership within the senior management team.
4. Capacity building is central to the Rurban approach and needs to be integrated into all aspects of the project. This cannot occur without engaging the community throughout the process – building the knowledge, skills and relationships required to enhance and sustain quality hospice palliative care across the health region.

Recommendations

I. Establish RQHR as a Rurban Demonstration Site for Phase II & III

Building on the success of Phase I, it is recommended that the Pallium Project in collaboration with RQHR, establish the RQHR as a Western Canadian demonstration site for the Rurban Hospice Palliative Care Approach (Phase II & III). Pallium and RQHR would continue as partners in funding and championing the project.

II. Proceed with Phase II in RQHR

It is further recommended that the RQHR begin implementation of Phase II within the next three to six months in order to maintain the interest and momentum built during Phase I. The transition to Phase II will require securing ongoing funding and leadership for the project, prioritizing the Strategic Directions developed in Phase I and establishing working groups and pilot sites within the region.

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Supporting a Meaningful End of life

The journey toward death – though always difficult – can be a rich and profound experience that gives meaning and completeness to life.

His mother's wish was to die at home surrounded by the people she loved and the things that had given her such joy during her life. Home Care brought in oxygen and a hospital bed and supported the family in actively caring for their mother in the way they chose, until she died.

When Sarah's grandfather died the large extended family that filled the hospital room and spilled out into the hall was able to honor the traditions of smudging, offering prayers and remaining with the body of their loved one. Ten years earlier this had not been possible when her aunt had died in the same rural hospital.

The need for quality end of life care in Canada is growing as the population ages and as attitudes shift. The challenge of providing quality palliative care is perhaps most acutely felt in the rural and remote areas where there are fewer specialists and less access to health resources.

At the same time, the remarkable accomplishments and innovative responses by rural hospice palliative care providers are an inspiration, offering insights into how care for the dying can be enhanced at the local level.

Hospice Palliative Care is care that aims to relieve suffering and improve the quality of living and dying.

The Rurban Hospice Palliative Care Project, undertaken by the Regina Qu'Appelle Health Region in partnership with Pallium Project (Phase II), set out to develop a model for providing quality hospice palliative care across the rural and urban areas within a regional health authority.

This report provides a description of the model, an overview of the process used to develop it and an outline of the first phase in applying the model within the Regina Qu'Appelle Health Region.

Note: In this document the Regina Qu'Appelle Health Region will be referred to as RQHR.

1. Project Framework

Developing a primary health care approach for hospice palliative and end of life care within regional health authorities.

Creating a Model

The impetus for the Rurban project is a practical one – to address the very real need for enhancing hospice palliative care services available in rural communities within Regina Qu'Appelle Health Region. The approach has been 'learning by doing' and extrapolating from the real life experience a conceptual framework or model that could be shared with others.

Rurban is a term coined to describe an approach where hospice palliative and end of life care services within a Regional Health Authority are organized to deliver comprehensive, consistent, and accessible care throughout the region.

Support structures enable rural and urban communities to work collaboratively in providing access and ensuring quality of care and sustainability. The approach recognizes both the common and unique challenges faced by the communities and consciously builds on the strengths and resources of the rural and urban areas to address these challenges.

The Rurban approach recognizes that while services may be 'comprehensive, consistent and accessible' throughout the region, they will not be the same services i.e. bereavement care in an urban area will not necessarily be provided in the same way in a rural area.

Primary health care is an approach that focuses on patients, clients and families, and communities working with a team of health professionals. The community participates in identifying its own health needs and planning for local health services

The overall **purpose** of the Rurban Project is to develop a primary health care approach for hospice palliative and end of life care within regional health authorities.

The **intended outcomes** of the project are:

- A **flexible, sustainable model** for providing hospice palliative care that utilizes existing health care and community services across the rural and urban areas of the health region.
- A **process road map** to guide other regional authorities across Western Canada who wish to adapt the model to meet the specific/unique characteristics, needs and resources in their communities.
- **Strengthened community** relationships, confidence and ownership as a result of the collaborative process used to develop the model.
- **Application** of the Rurban model in building the Regina Qu'Appelle Health Region approach to hospice palliative care throughout the region.

The Guiding Principles

The beliefs and principles that guided the project emerged early in the process and were



reaffirmed through the community meetings and family interviews. These principles deeply influenced how the project proceeded, what was found and the model that was developed. Six principles helped guide the project:

- **Community Building and Collaboration:** Central to the Rurban approach is the engagement of the community in: identifying its requirements for end of life care: the data gathering; and, the adaptation of the model. This is a conscious strategy for strengthening community commitment, confidence and capacity and for ensuring local relevance and sustainability.
- **Appreciative Framework:** Beginning with existing strengths, what people know and the *'best of what is'*, forms the foundation of the Rurban approach. The intent is to build on local creativity, commitment, confidence and ownership. This is a conscious shift from issue-based to a strength or asset -based approach.
- **The Human Experience:** What brings meaning to end of life differs between individuals and is rooted in what has been meaningful during one's life. The heart of Rurban hospice palliative care is the acknowledgment of death and the intention to relieve suffering in a way that meets the family where they are to help create a peaceful end of life.
- **Respect for Culture, Traditions and Ethnicity:** Individual experiences of grief are similar in different cultures, yet there are different ceremonies, traditions, and behaviors to express grief. Core to the Rurban model, is the recognition that helping families cope with the death of a loved one must include respect for the family's culture, traditions and ethnic heritage.
- **Rooted in Best Current Practices & Innovation:** Best current practices and evidence-based research provide knowledge of the *'best of'* hospice palliative care. Necessity as the mother of invention, has led to innovative and creative ways of delivering care in rural areas. The Rurban model draws on and strengthens both. It recognizes learning and change occur in the 'place of practice'.
- **Systems Approach:** A systems approach encompasses the larger picture of the whole system of inputs, processes, outputs, feedback, and controls. The intent of the Rurban model is to create integrated, seamless hospice palliative care services. The systems approach helps build and maintain linkages.

Project Leadership and Structure

Project leadership was provided by an Advisory Committee, a Steering Committee, the Palliative Care team, and, a consultant team. Regina Qu'Appelle Health Region in partnership with Pallium Project (Phase II), championed the project. The advisory committee provided overall conceptual guidance. Members included:

All Canadians have the right to die with dignity, free of pain, surrounded by their loved ones, in the setting of their choice. (CHIPCA)

- Executive Director of Family Medicine, Home Care and Palliative Care and the Executive Director of Rural Health Facilities
- Director of Palliative Care Services
- Director of Strategic Corporate Development
- Dr. L.J. Clein, Medical Director & Dr. J.S. McMillan, Palliative Care Physician



The steering committee, chaired by the Director of Palliative Care Services, provided ongoing guidance for the project. The committee included members of Rural and Urban Palliative Care Service Delivery Teams & Management, and the Consulting Team. [See Appendix F] Phase I of the project spanned an eleven-month period from May 2005 to March 31, 2006.

Key Definitions Used in the Report

Canadian Hospice Palliative Care Association (CHPCA) is the national association that provides leadership in hospice palliative care in Canada.

Hospice palliative care is a special kind of health care for individuals and families who are living with a life-threatening illness that is usually at an advanced stage. The goal of palliative care is comfort and dignity for the person living with the illness as well as the best quality of life for both this person and his or her family. (CHPCA)

End of life care is skilled, compassionate, and respectful care at the end of life. It includes service delivery by interdisciplinary teams; access to services in the most appropriate location; around the clock services; availability of services before death is imminent; services for all, with respect to cultural background and type of illness; awareness and skill in pain and symptom management; and support for caregivers and family. End of life care includes all end of life situations (Quality end of life care: the right of every Canadian, 2000).

Family is whoever the person says his or her family is. It may include relatives, partners and friends. (CHPCA)

Community of Care (CoC) encompasses the health care providers, patient, family, volunteers and members of the community (spiritual counselors, lawyer, funeral home, community organizations, etc.) who together assist in creating a meaningful end of life experience for the palliative patient and his/her family

Culture can be defined as having a common pattern of communication or language unique to the group; similarities in dietary preferences and preparation methods; common patterns of dress; predictable relationship and socialization patterns among member of the culture; and a common set of shared values and beliefs.

Ethnicity is based on the sense of identity an individual has based on common ancestry and national, religious, tribal, linguistic, or cultural origins. It generally implies that there are shared values, lifestyles, beliefs, and norms among those claiming affiliation to a specific ethnic group.

The terms **Client** and **Patient and Family**, are used interchangeably.

Approach and Methodology

An **action research** design was used in the project. Action research is collaborative research that develops from a shared goal to improve practice, in this case the delivery of hospice palliative care in rural communities. Action research aims to improve practice in cooperation with participants, shaping the changes or models to be implemented.

The communities used their understanding of the *'best of what is'* to construct a vision of how rural palliative care *'could be'* within their community.

The initial step, and the one that fundamentally set the direction for the project, was to frame the consultations, research and design around the question of: *What is and what supports a meaningful end of life experience?*

Guided by this clear sense of direction and intent, the next step in project design was to articulate the broader health care **context** within which the development of a Rurban model of hospice palliative care would take place:

- The population health approach that recognizes many interconnected factors and conditions contribute to health (determinants of health)
- Primary health care with its focus on the active participation of individuals and communities in the development and delivery of effective health care services.
- The philosophy and current best practices of hospice palliative care along with care delivery models i.e. the Square of Care and Organization (CHPCA)
- The specific characteristics of and factors that influence RQHR i.e. there are seventeen First Nations Reserves within the region.

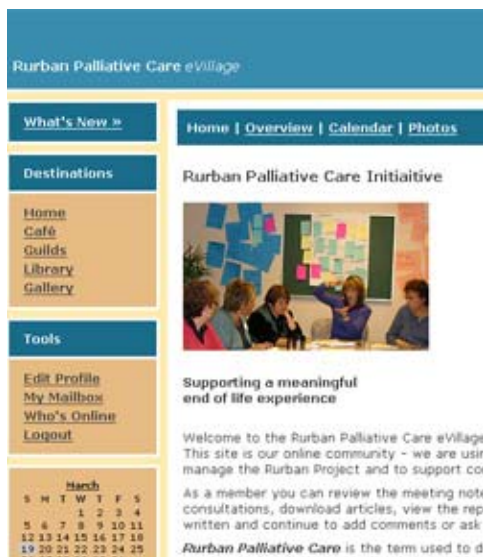
The project methodology drew heavily from community development and capacity building theory, strength/asset based approaches (appreciative inquiry- see Appendix A), and systems thinking. It is generative in nature, meaning there is a conscious intention to build capacity within the system by helping people to rethink how they work and relate.

Seven half-day community meetings [See session agenda in Appendix H] were held in addition to meetings with First Nations, rural physicians, researchers and a larger stakeholder group. Interviews were conducted with seven families, resources gathered on current best practices and an interactive web site established.

The community consultations and family interviews allowed people to talk about where they had witnessed, been part of and/or contributed to a *'meaningful end of life experience'*. Using a paired interview process the participants identified the conditions or factors that contributed to the experience i.e. community supports, leadership, equipment and clinical competence. The factors were themed and became the **Components of Care**. They were then further developed as 'provocative statements' – descriptions of the desired future, boldly stated [Appendix A]. This rich synthesis of the consultation and research data was used to identify the broad strategic directions or goals for developing and enhancing hospice palliative care across the rural and urban areas of the health region.

Innovative Use of Technology

An interactive web site, using collaboration software, was incorporated into the project. The purpose was to begin experimenting with practical uses of technology to support online project management and to enhance community engagement, relationship and capacity building.



The Rurban Palliative Care *eVillage* provided an online space where participants could continue to contribute their thoughts and ideas; view a summary of the discussions held at each of the community meetings; review the report as it was written; download articles; and, dialogue with members of the other communities involved in the initiative.

Within the scope of Phase I of the project, the *eVillage* offered an initial exposure, an introduction to the concept and technology.

In Phase II the intent will be: to manage the overall project and support the working groups by creating team collaboration areas in the eVillage; and, to incorporate the 'social processes' needed to facilitate ongoing dialogue, feedback and learning within the broader project community.

Building collaborative communities, whether online or in person, share similar requirements - a common purpose; clear direction, leadership and facilitation; information and feedback loops; and, a compelling reason to participate. In a community-based project spanning a large geographical area, such as the Rurban Project, the technology can significantly enhance: project collaboration, cross-community and facility communication, project tracing, the sharing of knowledge and best practices and networking.

As the project unfolds, the *eVillage* offers a venue where knowledge can continue to be collectively developed and shared i.e. what is a *meaningful end of life* and what strategies need to be implemented and tested to support access for all to quality end of life care? The Community of Care as the 'place of practice' is the most potent locale for change and learning to occur. Technology, effectively used, can provide practical, tangible support for practitioners, volunteers, community and family members (CoC), to individually and collectively reframe how they work and relate.

2. Model & Process Map

All palliative patients and their families are entitled to the comfort, compassion and clinical competence needed to maintain dignity and to experience a meaningful end of life.

The Rurban Hospice Palliative Care Model

Drawing from the community consultations, interviews with families, research on best practices and review of existing 'models', a Rurban approach emerged along with a statement of the Rurban **philosophy**:

We believe all palliative patients and their families are entitled to the comfort, compassion and clinical competence needed to maintain dignity and to experience a meaningful end of life. This encompasses the physical, psychological, social, cultural, emotional and spiritual needs of the individual.

The assurance that this level of care is available throughout a region is built on the collaborative efforts between rural and urban areas and on developing creative services with flexible programming to meet the unique needs of the individual, family and community.

The Rurban model illustrates an approach for engaging communities in the development and/or enhancement of their hospice palliative care services. The model is a diagrammatic way to illustrate the key concepts and the dynamic relationship between the parts, in a non-linear manner. The purpose of the model is to enhance the understanding of the concepts being illustrated and provide a framework for replicating the approach.

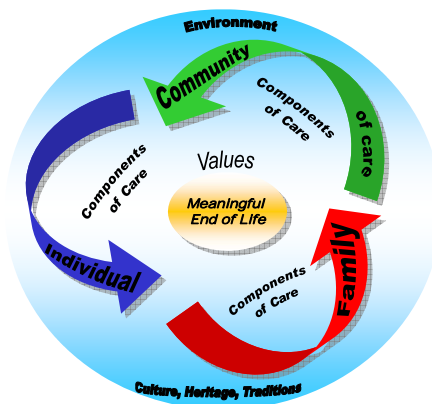


FIGURE 1 - This is the generic version of the Rurban Model. [See Appendix B]

In the Rurban Model . . .

A *Meaningful end of life* is located at the center of the model. It is the vision - the desired and intended outcome. Placing a *meaningful end of life* at the center illustrates the application of a patient-centered approach and is the key focus in how the components of care are developed, articulated and delivered.

The colored arrows represent the three *Dimension* of care - the Individual, the Family and the Community of Care (CoC). The *Dimensions* denote the three groupings that participate in the end of life care – both in contributing to and receiving care. The arrows illustrate a relationship and flow between the dimensions.

I expected quality care for my Dad; I didn't expect to be cared for myself, but I was and it made such a difference.
- Family Member

The *Components of Care* are developed by the regional health authority in partnership with the communities starting with the question *what supports a meaningful end of life?*

The blue shaded area represents the environment: the *values, culture, traditions, geography, unique characteristics and specific requirements* of the health region. These form the **context** and influence the components of care that emerge through the process.



Relationship Between the Rurban Model and Other Hospice Palliative Care Models

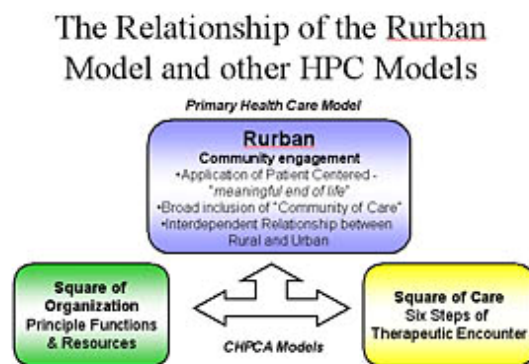
The goal of the Rurban Project is to develop a primary health care approach for hospice palliative and end of life care within regional health authorities.

The Rurban model provides a framework for community engagement. Grounded in the practices of community and capacity building, it supports the broad inclusion of health care providers, volunteers, community members, patients and their families in the process of developing and/or enhancing hospice palliative care services within the health region.

In this way it looks beyond the therapeutic encounter between the health provider(s) and the patient/family, to encompass the assets, strengths and resources within the community. The Rurban hospice palliative care model creates a framework in which the Square of Care- 'Therapeutic Encounter' (CHPCA) and Square of Organization (CHPCA) may occur.

The Square of Care (CHPCA) is a process for providing care through the six steps of the Therapeutic Encounter focusing on the issues (or domains) the patient and family commonly face. The intent is to alleviate suffering and pain of someone who is dying or at 'any point during an acute, chronic, or life-threatening illness, or bereavement.'

The Square of Organization (CHPCA) describes the (administrative) functions of a hospice palliative care program and the resources (financial, human, informational, physical, community) required to function and provide care in a safe, ethical, responsive compassionate manner. **Source:** A model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice (CHPCA).



The results of the Rurban community engagement process will inevitably influence and help shape the domains of the therapeutic encounter as well as the resources and administrative functions required to deliver effective hospice palliative care.

FIGURE 2 - shows the relationship between the Models. [See Appendix C]

The Process Road Map

The development process, from initial introduction of the Rurban hospice palliative care model as a *strategic initiative*, to an established operational program within a regional health authority, involves three phases over approximately a 2-3 year period:

Phase I: Setting the Course

Phase II: Program Development and Implementation

Phase III: Evaluation and Normalization

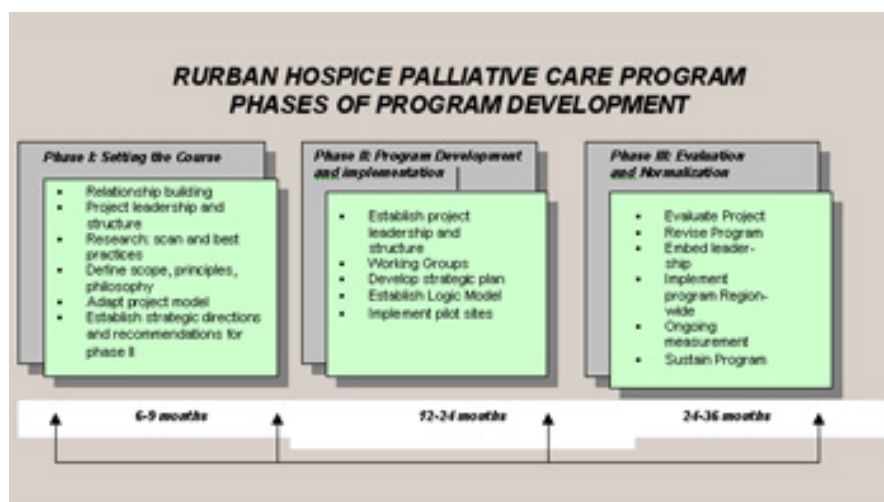


FIGURE 4 - The diagram outlines the steps in each of the three phases. [See Appendix D]

The steps in Phase I, as the focus of the work to date and of this report, are described in generic form below. In the following section, the RQHR adaptation of Phase I is described.

Phase I: Setting the Course

The focus of Phase I is to create the framework, structures and processes that will support the extensive community engagement and participation inherent in this model. Formal and informal community consultation begins in Phase I and is woven through Phases II & III.

- **Relationship Building:** Identify and bring together the key stakeholders to determine commitment and leadership i.e. identify local 'champions', include key ethnic and cultural group such as First Nations and Metis, at on the onset.
- **Project Leadership and Structure:** Determine the committee structure, leadership, the skills and the time required. Working in partnership with the communities and strategically building capacity throughout, brings a complexity to the initiative. It is one that cannot be done 'off the side of someone's desk', in the initial development stages. Later, as it becomes anchored into the operational plans, it can be resourced accordingly.

- **Community Consultation:** Engage health care workers, volunteers, community members and family members in a series of community gatherings and individual interviews.
- **Environmental Scan and Best Current Practices:** Research demographics, services and facilities within the region and more broadly current best practices and innovations to create a contextual framework for the initiative.
- **Define Scope, Principles, and Philosophy:** The Rurban model includes a philosophy, principles and definitions. Each region will need to determine the scope of their own initiative and review the foundations of the model.
- **Adapt Project Model:** The model provided is a pilot. It was developed through action research and is being field-tested in the RQHR. The intent is to illustrate an approach for working with the communities in developing and enhancing hospice palliative care. Other regions are encouraged to work with the model and share their adaptations.
- **Establish Strategic Directions and Recommendations for Phase II:** The first Phase moves through: data gathering; identification of the vision, values and broad based themes; the creation of the components of care with provocative statements providing a picture of ‘success’; the strategic directions and recommendations for Phase II.

Phase II: Program Development and Implementation

The focus of Phase II is to continue to build on the community involvement and ownership, through engaging members of the Community of Care in the working groups, development of the strategic plan, and the design and delivery at the pilot sites.

- **Establish project leadership and structure**
- **Working Groups**
- **Develop Strategic Plan & Establish Logic Model**
- **Implement Pilot Sites**

Phase III: Evaluation and Normalization

The focus of Phase III, in partnership with the community is to evaluate the pilot site(s), integrate the learning into the program, broaden implementation and embed the program into the operational plans of the health region.

- **Evaluate Project**
- **Revise Program**
- **Embed Leadership**
- **Implement Program Region-wide**
- **Ongoing measurement**
- **Sustain the Program**

3. Application: RQHR

Best current practices point to the importance of community involvement, community voice and a community development approach to service development.

Rurban: A Strategic Initiative

The Rurban Hospice Palliative Care Project is linked as a *program/ service initiative* within the Regina Qu'Appelle Health Region Strategic Plan. It supports:

Strategic Theme 4: Primary Health Care- *Improve health status though supporting individuals and communities in responsibility for their own health through service redesign.* **Goal C2:** *Accessible services that are responsive to community and individual needs.*

Strategic Theme 3: Aboriginal Health- *Improve health status outcomes for Aboriginal people through coloration.* **Goals: Q2 & Q3 -***Build culturally sensitive service delivery processes and Enhance collaboration through partnerships.*

More broadly, it supports **The Saskatchewan Health Action Plan, Goal Four:** *Improve access to quality health services.*

The action research approach used in this project has required two parallel processes be undertaken simultaneously. During Phase I this involved developing the model, philosophy and principles for the broader project using RQHR data, and then applying the RQHR data back into the model as a demonstration site.

A process road map for RQHR is provided below. The steps in Phase I, as they related to the RQHR application, are described in detail.

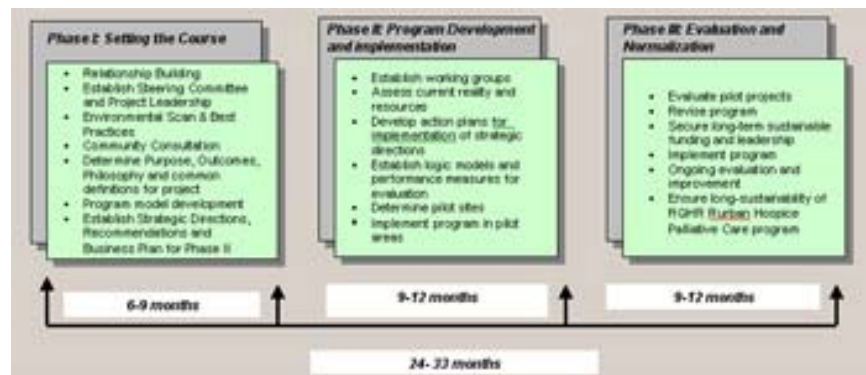


FIGURE 5 - The three phase process road map for RQHR..[Appendix E]

Phase I - Setting the Course

- **Relationship Building:** A broad stakeholder group, comprised of rural facility managers and service delivery professionals representing different portfolios in the region, met in May 2006. The focus of the meeting was to explore the intent of the Rurban initiative and determine community commitment and leadership.
- **Establish Steering Committee and Project Leadership:** The Steering Committee was formed, comprised of the Regional Facility Managers. The Director of The Palliative Care Unit, RQHR provided project leadership with project design and direction shared between the internal and external consultants.
- **Environmental Scan & Best Current Practices:** An overview of the demographics and baseline information on facilities and services within the region [Appendix I] was gathered and research on best practices in hospice palliative care, local, national and international in scope, undertaken [see References]
- **Determine Purpose, Outcomes, Philosophy, Principles and Common Definitions:** In the parallel process of developing and applying a model, this is where the foundation pieces were developed for the Rurban model.
- **Community Consultation:** Health care workers, volunteers, community members and family members attended a total of seven community consultation sessions, seven family interviews, and a series of meetings with physicians, researchers and First Nations' representatives.
- **Program Model Development:** The data gathered through the interviews, meetings and consultation sessions was used first to develop the model, and then applied to the model in the RQHR application.
- **Establish Strategic Directions, Recommendations and Business Plan for Phase II:** The development process moved through: data gathering; identification of the vision, values and broad based themes; the creation of the components of care with provocative statements providing a picture of 'success'; the strategic directions and recommendations for Phase II.



These key processes and ‘deliverables’ are outlined in the strategic framework schematic below:

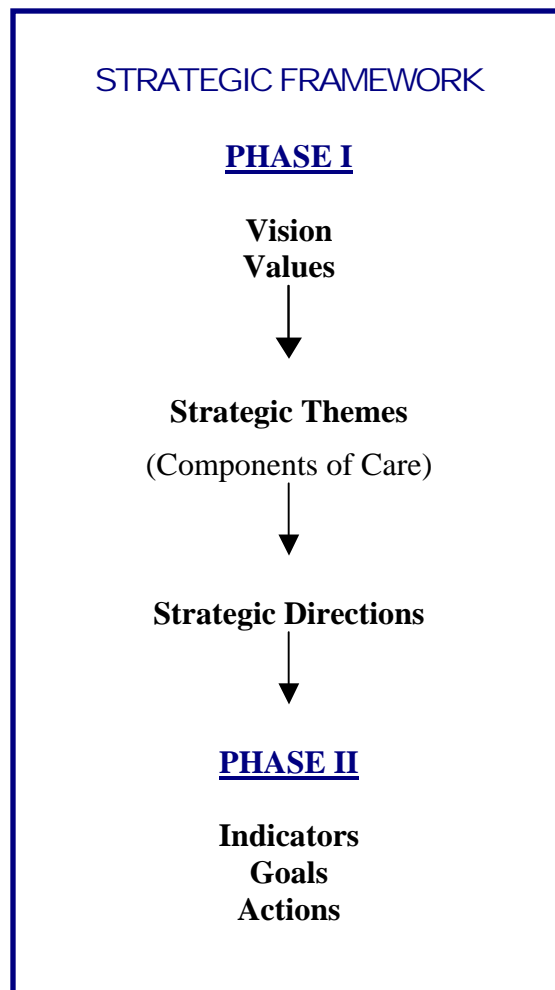


FIGURE 6 –The RQHR Rurban Project Vision, Values, Strategic Themes (Components of Care), Strategic Directions and Phase II steps can be found in Appendix M

Components of Care

The **Components of Care** represent the essential core elements that together help create a meaningful end of life experience. They were developed from the broad strategic themes gleaned during the community consultations. [See Appendix K]

*My Mother gave me
a gift in her dying –
she gave me a way to
see life differently.
- Family Member*

Physical Comfort: The patient is comfortable - physical pain and symptoms are managed to enable meaningful interaction with loved ones until the time of death. The effective management of advanced pain and symptoms is provided through the use of appropriate therapeutic methods, equipment and material resources.

Spiritual Well-Being: A holistic approach addresses spiritual, emotional, social and physical pain. Care providers assist the patient to discover opportunities for growth at the end of life. The patient and family is supported in their suffering in a way that is meaningful, maintains personal integrity, and is sensitive to their cultural traditions and personal preferences.

Family Focused: The death of a loved one is a very personal experience. Families are encouraged and supported in deciding how the care of their loved one will unfold – leading the dance where they can and drawing on the expertise and strength of the care providers, as they require.

Acknowledge and Accept:: Dying is an integral and fundamentally human aspect of living. The acknowledgement and acceptance of death, although difficult, can bring meaning and a profound sense of being alive in the moment, for the patient, family and caregivers.

Knowledge and Competence: The broader community of care has the skills, knowledge and capacity to support end of life.

Continuity of Care: Access and continuity of care is enhanced in rural areas through flexible use of existing services, and effective coordination.

Sustainable Leadership and Structure: The RQHR Rurban Hospice Palliative Care Initiative is sustained through strong, shared leadership between RQHR and the Community of Care. This strong alliance ensures each palliative individual and family has an opportunity for a meaningful and supported end of life experience.

Creative Integration of Community Resources: The integrity of communities is preserved while capacity is enhanced through greater integration of resources between the communities, rural and urban. Independence and interdependence are fostered.



Rurban Model: RQHR Application

The **Components of Care**, developed by the Steering Committee using the RQHR consultation and research data, were placed beneath the **Dimensions** in the model. Although some of the Components related more to one Dimension i.e. Physical Comfort and Spiritual Well-Being were seen as focusing primarily on the patient (Individual), it was also recognized that each of the Components of Care flow between the Dimensions. For example, the acknowledgement and acceptance of death as an aspect of care, touches the individual, family and broader community of care.



FIGURE 6 – The values identified by the RQHR and the Components of Care developed through the community engagement process are placed within the model. [See Appendix J]

The **values** identified as core in adapting the Rurban Model within the RQHR were **courage, knowledge, access for all, respect and compassion**. These were seen as the crucial underpinnings in supporting a *meaningful end of life*.

The context or environment –*culture, traditions, geography, unique characteristics and specific requirements* of the RQHR- are reflected in the Components of Care that emerged from the consultation data.

Considerations inherent within the RQHR environment include: seventeen reserves; First Nations governance structures; both Federal and Provincial health care providers and facilities; growing diverse population especially in urban area; and, the amalgamation of three separate districts. In addition, the Canadian Council on Health Services Accreditation (2005) identified the need to:

- Continue to develop strategies to serve clients outside the urban area of the region such as through the national ‘rurban’ initiative. This is important following the changes that have been made to regional boundaries. The financial barriers experienced by some people, in the most part, relate to general end of life challenges.
- Assess satisfaction with the bereavement services in rural areas [to address the unique bereavement issues of Aboriginal clients and people living in rural and remote areas of the region.]

Strategic Directions

Strategic Directions are broad statements signifying a clear shift in direction. They can be measured, will result in multiple actions, and encompass both current service elements and beyond.

The Steering Committee, along with members of the broader stakeholder group, worked with the Components of Care to develop eight Strategic Directions that will guide the RQHR Rurban Project as it moves into Phase II. They are:

- 1. Establish a Culture that Supports Hospice Palliative Care**
Principles of hospice palliative care that acknowledges death as an integral part of life are integrated into all aspects of hospice palliative care practice and care delivery.
- 2. Advance Knowledge through Education**
All levels of the Community of Care have the knowledge and capacity (reflective of the appropriate scope of practice of the CoC) of the philosophy, principles and the standards practices of effective hospice palliative care.
- 3. Strengthen and Preserve the Integrity of the Family**
All processes of providing care such as information sharing, decision-making, care plan development and care delivery are developed and implemented in consideration of the unique dynamics within each family.
- 4. Expand Innovation and the Use of Technology**
Innovative methodologies are used for knowledge exchange, skill development and to link the CoC across geographic distances i.e. practice site exchanges, the use of healthlines, teleconferencing etc.
- 5. Enhance Access and Coordination**
All RQHR citizens have access to hospice palliative care and the necessary community supports, regardless of location, culture and social economic status.
- 6. Embed a Shared Leadership Model**
A shared leadership model with the CoC encourages creativity in resource allocation and builds strong collaborative relationships within the Community of Care.
- 7. Establish Resource Management Processes**
The RQHR has established a process for the pooling and sharing of resources, ...skills, unique approaches to service delivery and physical resources.
- 8. Honor Culture, Heritage and Tradition**
Appropriate supports for palliative patients and families in the RQHR are in place for Aboriginal people and people of other cultural and ethnic groups.

Note: A more complete description of the Strategic Directions and initial work done to identify possible goals and actions can be found in Appendix L.

In Phase II, the working groups will further develop the Strategic Directions. One of the tasks early on in Phase II is to prioritize the Strategic Directions and determine which ones will be incorporated into the pilot sites.

A brief description of Phase II and III is as follows:

Phase II - Program Development and Implementation

The focus of Phase II is to continue to build on the community involvement and ownership, through engaging members of the Community of Care in the working groups, development of the strategic plan, and the design and delivery at the pilot sites.

Phase III - Evaluation and Normalization

The focus of Phase III in partnership with the community is to evaluate the pilot site(s), integrate the learning into the program, broaden implementation and embed the program into the operational plans of the health region.

Conclusion and Recommendations

Just as dying is part of the life of an individual, and part of the life and history of a family, caring for those among us who are dying is part of the ongoing life of the community. Ira Byock

The Rurban project undertaken by RQHR in partnership with the Pallium Project (Phase II), was designed to establish a foundation for enhancing hospice palliative care in the rural areas, and to approach it in a way that engaged the community in the identification, analysis and design of the initiative.

The response was overwhelming - community sessions involving practitioners, volunteers and community members were filled to capacity, family members generously shared their experiences during the private interviews, and the rural physicians spoke candidly of what brings a deep sense of meaning to their work with palliative patients and of the supports they require as care givers.

The following findings and recommendations emerged from Phase I of the project.

Key Findings

- i. **Community Engagement** Response to the project and the quality of the input reaffirmed the importance of meaningful community involvement. The readiness within the communities to work together highlighted the need to maintain the momentum by moving as quickly as possible into Phase II. Community-based collaboration and focused capacity building do, however, require time, resources, skill and the commitment to foster the relationships and to ensure all the key stakeholders are brought to the table at the onset i.e. in the RQHR this includes Aboriginal representation.
- ii. **Framing the Process** How the project is framed makes a world of difference! In the Rurban Project the decision was to focus the discussions and research on a *meaningful end of life*, firmly placing the patient at the center of the development process. This, in addition to the use of an appreciative approach, helped to create a sense of ownership and confidence for building on the foundation of what is presently being done within the communities to support a *meaningful end of life*. The framing also recognized that while services may be 'comprehensive, consistent and accessible' throughout the region, they will not necessarily be provided in the same way.

- iii. **Leadership** The Rurban approach denotes a shift in how palliative care is developed and delivered across the rural and urban areas of a health region. Leadership is crucial in terms of a project leader with the skills and resources to guide the project, community leaders and champions and the senior management team within the health region. The Rurban model requires a rethinking of the knowledge and skills leaders need in order to facilitate the changes that will be ongoing as the need for palliative care continues to increase.
- iv. **Building Capacity** Strategically building capacity is central to the Rurban approach and must be integrated into all aspects of the project. This cannot occur without engaging the Community of Care throughout the process – building the knowledge, skills and relationships required to enhance and sustain quality hospice palliative care across the health region.

Recommendations

Based on the experience and outcome of the Rurban Hospice Palliative Care Project Phase I, it is recommended that the project continue through Phases II & III. There are two overarching recommendations: 1) That RQHR and Pallium Project designate RQHR as the Western Canadian demonstration site for the continuation of the project, Phase II&III; and, 2) That RQHR regardless of whether it is designated as a demonstration site, move to Phase II in implementing the model within the health region.

I. Establish RQHR as a Rurban Demonstration Site Phase II & III

Building on the success of Phase I, the Pallium Project in collaboration with RQHR, establish the RQHR as a Western Canadian demonstration site for the Rurban Hospice Palliative Care Approach (Phase II & III).

1. Partnership Agreement

Establish a Partnership Agreement outlining roles, accountabilities, deliverables and outcome measures.

2. Resources

Determine and allocate the required shared financial, human, knowledge and administrative resources for the project.

3. Technology

Embed the innovative use of technology into the project design. Identify intended outcomes and measures and continue to explore combining technologies i.e. collaboration software and telehealth, to effectively project manage online, maintain feedback loops and project transparency while supporting relationship and capacity building within the demonstration site and across Western Canada. This is a new frontier with a great deal to offer.

II. Proceed with Phase II in RQHR

Begin implementation of Phase II within the next three to six months in order to maintain the interest and momentum built during Phase I. Many community stakeholders were involved through the consultation process and there is a keen interest and willingness to work together on enhancing available palliative care services. The transition to Phase II will require securing ongoing funding and leadership for the project and establishing working groups to develop the action plan for moving forward.

1. Stakeholder Endorsement and Commitment

Present the project report and findings to the stakeholders (RQHR Executive Sponsors, Palliative Care Team, Rural Health Facilities, Pallium Project and community participants) for their feedback and endorsement and to establish commitment for Phase II. It is essential that the outcomes of Phase I be reviewed with the key stakeholders prior to moving to Phase II. A significant amount of human and financial resources have been invested in Phase I of the Rurban Hospice Palliative Care Project.

2. Shared Leadership

Establish a shared leadership model at the senior management level, with clear lines of accountability to provide a strong platform for the implementation for Phase II and III. The implementation of the Rurban Hospice Palliative Care Project in the Regina Qu'Appelle Health Region will cross over several management portfolios.

3. Aboriginal Strategy

Continue to work with the RQHR Aboriginal Department, Aboriginal practitioners and researchers, such as Dr Mary Hampton, University of Regina (Study of end of life services and aboriginal people), to re-orient hospice palliative care services that are culturally appropriate and effective for Aboriginal people. With seventeen reserves and a large urban First Nations and Metis population falling within the jurisdiction of the RQHR, this is imperative in the further development of the Rurban Hospice Palliative Care Project.

4. Expertise to Build Capacity and Pave the Way

The Rurban Project represents a significant shift in how hospice palliative care will be provided throughout the region. This will require an investment in time, energy and resources in order to help people do things in a new way. In Phase II and Phase III, strong project management methodology and expertise will be required to establish the project plan, facilitate the process and lead the working groups. In addition there will be an increased need for education and coordination as outlined in the Strategic Directions.

5. Establish Pilot Sites

Prioritize the actions derived from the Strategic Directions and establish 'pilot sites' where the strategies can be field-tested and evaluated prior to implementing the Rurban program region-wide. Pilot sites should be selected based on pre-established criteria and an indication of strong commitment on behalf of the pilot site community. A key resource will be the comprehensive work done by Dr. Mary Lou Kelley, Lakehead University, on the required 'community conditions' in developing palliative care in rural communities.

6. eVillage

In Phase II, it is recommended the *eVillage* continue to be used as a project management tool connecting the working groups, ensuring transparency in the process and fostering ongoing community dialogue. During Phase I, participants were introduced to the online collaboration tool, that served to augment the community consultation process and keep stakeholders apprised of the project as it progressed. The technology offers a potential boon for rural areas where people are separated by large geographic distances. It cannot take the place of face-to-face contact but can enhance the process.

7. Resource Requirements

Secure funding and resources for Phase II and III. If the pilots are successful the Rurban Hospice Palliative Care Model will be implemented region-wide as part of the RQHR Operating Plan and budget.

According to the CHPCA, with the number of deaths expected to increase 33% by the year 2020 and current access to hospice palliative care services for Canadians estimated at 15%, the need for access to quality end of life care is becoming greater than ever before.

The Rurban approach to developing and enhancing hospice palliative care offers an innovative community-based methodology for building the leadership, skills, commitment and structures required to support access to a *meaningful end of life* throughout a health region.



I wanted to be involved in the hands-on care of my father, but didn't know how. The staff showed me what to do...giving me the ability to have the intimacy I needed with my Dad during his process of dying. Family Member

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Whitney, D. & Trosten-Bloom, A. (2003) The Power of Appreciative Inquiry. Berrett-Koehler, CA.

Wood, S. Aiming Higher in Health Care: Appreciative Inquiry – a positive revolution in change. AIC Health Care Alliance

Publications and Web Links Posted in the Rurban Palliative Care Project *eVillage*

Appreciative Inquiry: The international Institute for Sustainable Development, applied appreciative inquiry. <http://www.iisd.org/ai/>

A Rural Palliative Home Care Model: Nova Scotia A comprehensive report on the Nova Scotia experience. <http://www.gov.ns.ca/health/downloads/Palliative%20Care.pdf>

Asset-Based Community Development <http://www.northwestern.edu/ipr/abcd.html>

Canadian Hospice Palliative Care Association Click on "Publications and Resources" and go to "A Model to Guide Hospice Palliative Care (Norms)" for National Principles and Norms of Practice. <http://www.chpca.net>

Canadian Virtual Hospice Information and resources on the physical, emotional and spiritual aspects of life-threatening illness. <http://www.virtualhospice.ca/Public/splash.asp>

Communities of Practice An introduction to Communities of Practice http://www.ewenger.com/theory/start-up_guide_PDF.pdf

Development of a Model for Palliative Care in Rural and Remote Communities. Describes a model for palliative care in rural and remote communities in Australia. <http://www.abc.net.au/rural/events/ruralhealth/2005/papers/popupmodel.pdf>

Growth House Guide to Palliative Care An overview of key issues in palliative care, with hypertext links to topic database. <http://www.growthhouse.org/cgi/search.cgi>

Living With Hope Video Helpful resource for those struggling to find hope in the midst of a life-limiting illness. <http://www.usask.ca/nursing/research/livingwithhope/video.htm>

Palliative Care in Rural Canada (U of R) Information on the components of a rural palliative care model based on the experience of care providers in rural Canada. <http://www.uregina.ca/spr/pdfs/paliative.pdf>

Pioneer Programs in Palliative Care: Case studies written by leaders and clinicians. <http://www.milbank.org/pppc/0011pppc.html>

Public Involvement Continuum - Health Canada A description of the different levels of public involvement. <http://www.phac-aspc.gc.ca/ph-sp/phdd/collab/collab2.html>

RQHR Palliative Care Programs and Services The programs and services provided through the RQHR. http://www.rqhealth.ca/programs/in_hospital_care/palliative_care/pall_prog_serv.shtml

Rural Community Health and Wellbeing: a Guide to Action A thorough example of the Logic Model for Evaluation. <http://www.brandonu.ca/organizations/RDI/Publications/guidebook.pdf>

Still Not There (Full Report) The progress and key areas still to be addressed to ensure that every Canadian can die with dignity. <http://sen.parl.gc.ca/scarstairs/PalliativeCare/Still%20Not%20There%20June%202005.pdf>

Still Not There: Key Points Key points from Senator Sharon Carstairs report on Quality End-of-Life Care. http://www.chpca.net/public_policy_advocacy/QELC_still-not-there-report/Key-points.pdf

The Pallium Project The Pallium Project (Phase II) is a national hospice palliative care development initiative funded by Health Canada. <http://www.pallium.ca>

TriCentral Palliative Care Program Toolkit A step-by-step guide on how you can create an innovative outpatient palliative care programs <http://www.growthhouse.org/palliative/>

Appendices

- A. Appreciative Inquiry: What is it?
- B. Rurban Model
- C. The Relationship Between The Models
- D. Phases: Generic
- E. Phases of Program Development (RQHR)
- F. Steering Committee Terms of Reference
- G. Family Interview Guide
- H. Session Agenda & Interview Guide
- I. Demographics & Baseline Data
- J. Rurban Model (RQHR)
- K. Components of Care: Provocative Statements (RQHR)
- L. Strategic Directions (RQHR)
- M. Strategic Framework (RQHR)

Appendix A – Appreciative Inquiry: What is it?

Appreciative inquiry is a strategy for purposeful change that identifies the best of "what is" to pursue dreams and possibilities of "what could be." It is a co-operative search for the strengths, passions and life-giving forces that are found within every system—those factors that hold the potential for inspired, positive change. The International Institute for Sustainable Development <http://www.iisd.org/ai/>

The Rurban Project used an appreciative framework to focus the research and discussions on *what is* and *what supports* a **meaningful end of life**. The strength of appreciative inquiry, as an approach to change, lies in the level of community engagement and the energy, commitment and sense of confidence and ownership it engenders

Appreciative inquiry shares similar principles to strength or asset-based approaches for community and capacity building. These methodologies identify and mobilize individual and community talents, skills and assets, rather than focusing primarily on problems and needs.

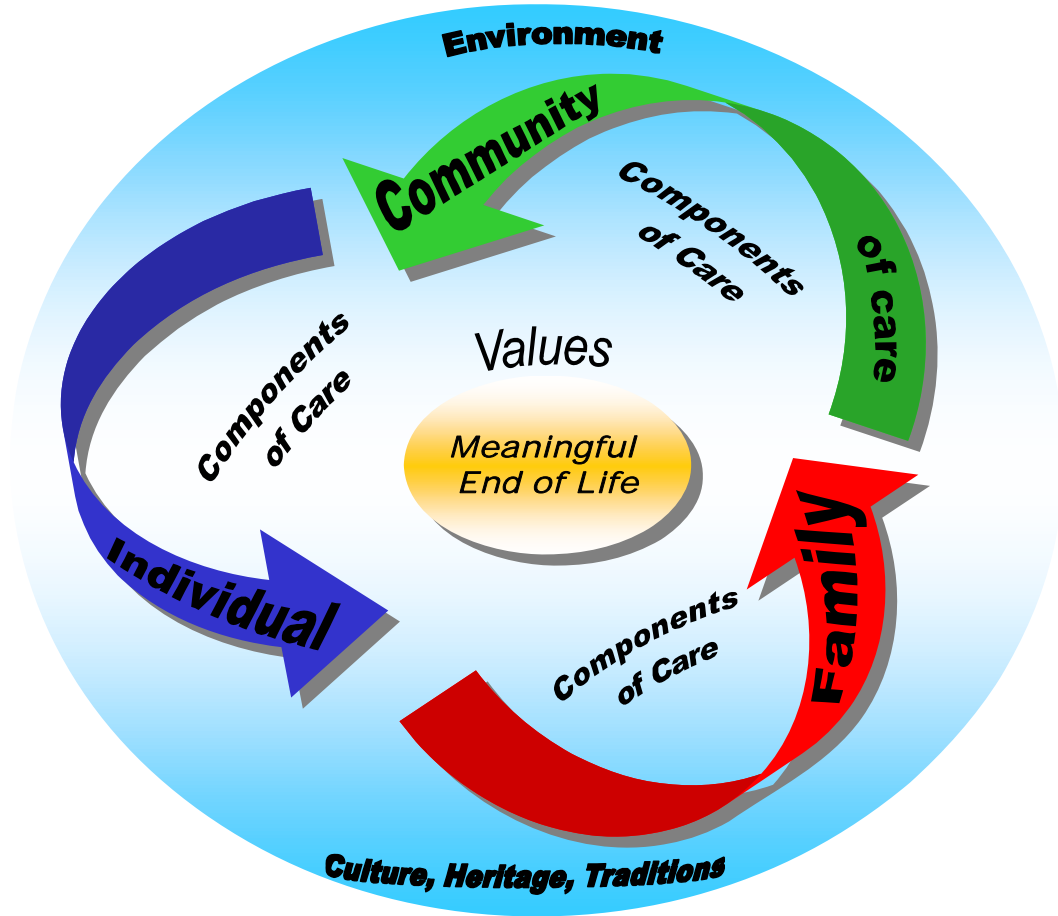
An appreciative approach is described as moving through four phases: the **discovery** of the strengths and the ‘best of what is’; the **dream** phase of envisioning a more valued and vital future – the ‘best of what could be’; the **design** of strategies to realize the dream; and, the actions that create and sustain the new envisioned **destiny**. These phases were incorporated into the Rurban Project as follows:

- The community consultations and family interviews allowed people to talk about where they had witnessed, been part of and/or contributed to a ‘meaningful end of life experience’. They identified the **conditions** or **factors** that were present and made it possible - such as leadership, relationships, community supports, technologies, values, equipment, skill and clinical competence.
- The factors that contributed to these successful experiences were themed and became the **Components of Care**.
- The Components of Care were further developed as **provocative statements** – descriptions boldly stated, in the present tense, that challenge the status quo and provide guidance for developing the conditions needed to consistently support ‘meaning end of life’ for hospice palliative patients and their families.
- These Components of Care were then used to identify the broad **strategic directions** or goals for developing and enhancing hospice palliative care across the rural and urban areas of the health region.
- In Phase II of the Rurban Project: working groups will further develop the strategies; pilots will be initiated; and, feedback loops established for continuous learning and improvement.

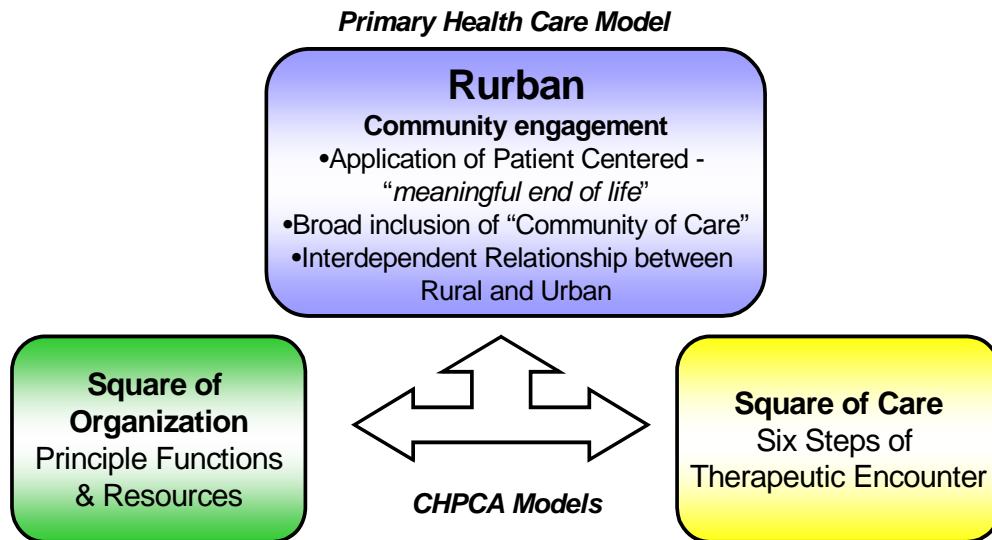
Note: The provocative statements describe what a *meaningful end of life* and how it is supported. Intended to inspire and energize, provocative statements (propositions) are:

- **Provocative:** stretch, challenge or interrupt the status quo
- **Written in present tense:** to describe current reality, as if it is already happening
- **Grounded:** illustrate the ideal or real, practical possibilities
- **Desired:** If you could have it, would you want it?
- **Affirmative:** boldly stated in the positive: We are... We do.... We have.....
- **Guidance:** clearly provide direction for the future

Appendix B – Rurban Model

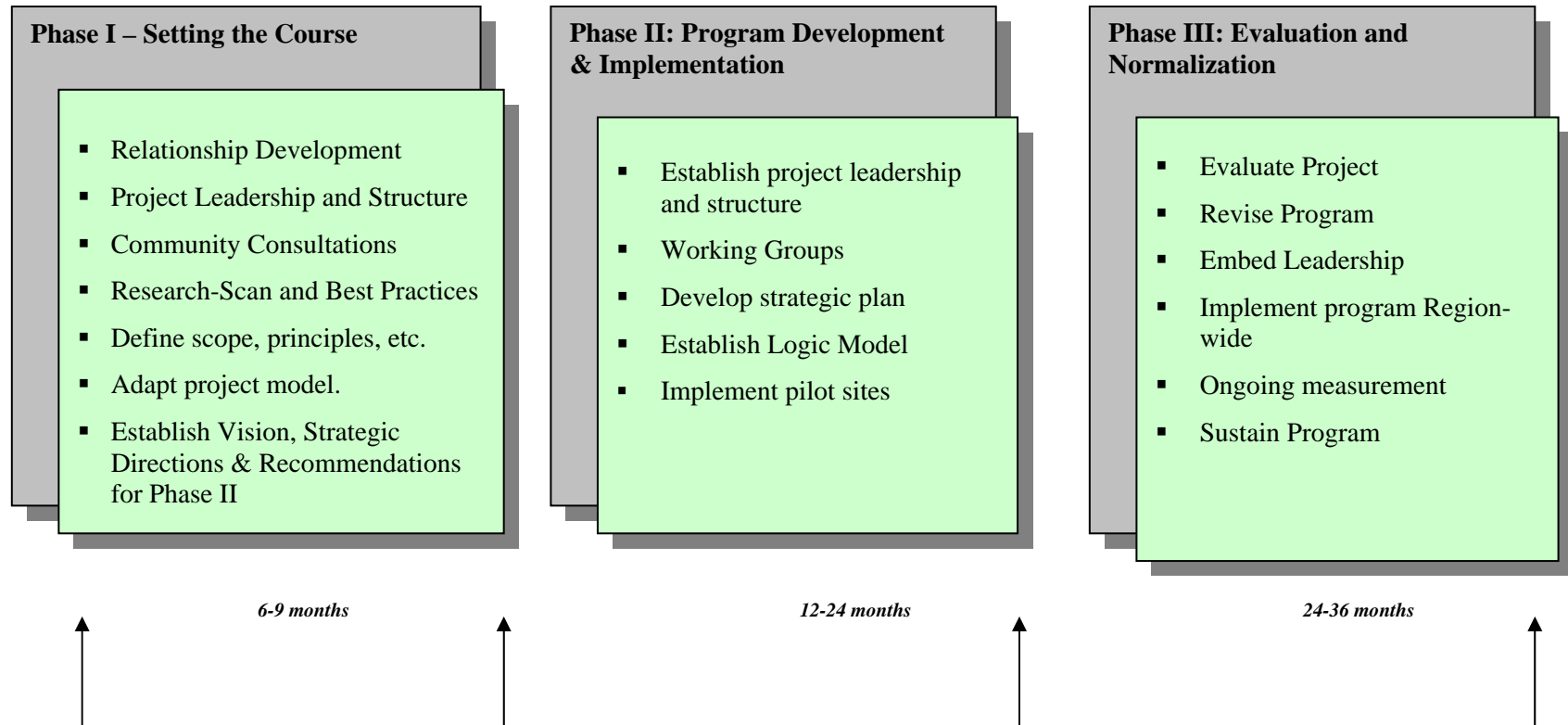


The Relationship of the Rurban Model and other HPC Models



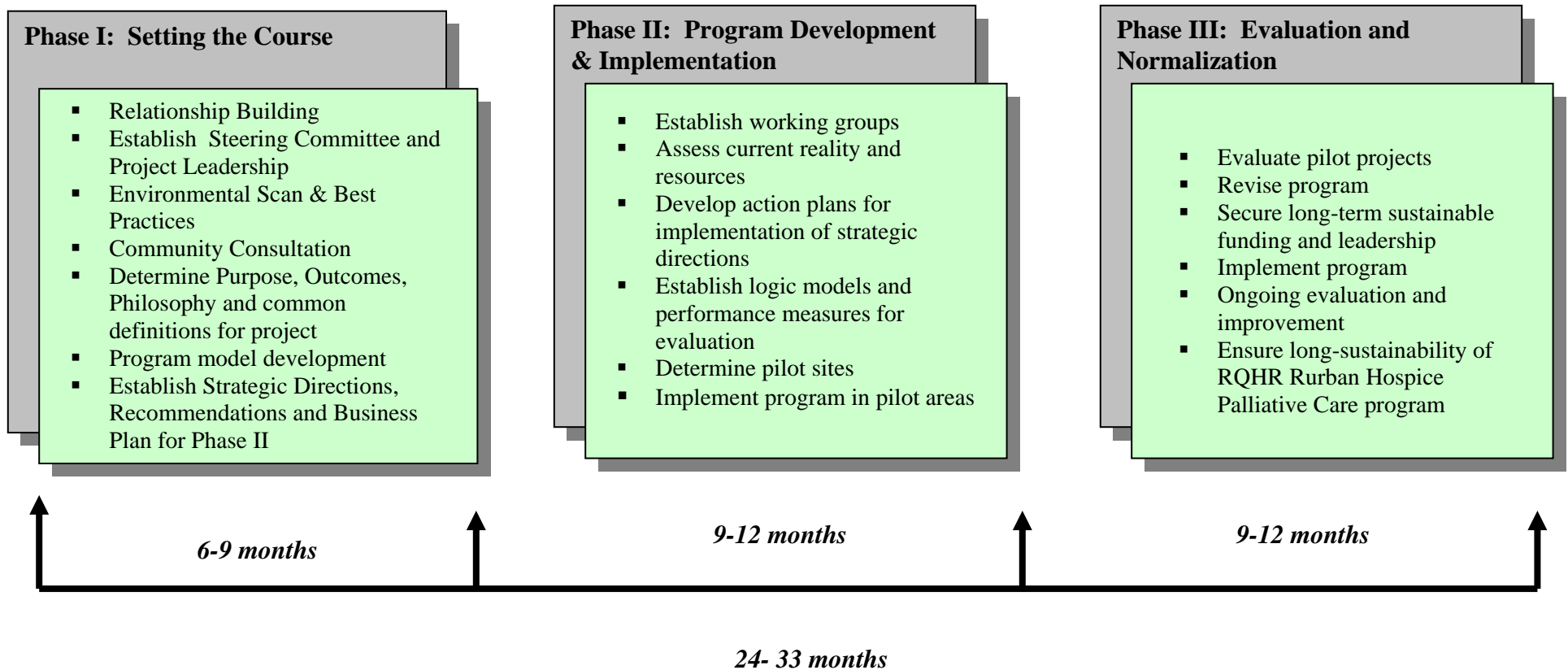
Appendix D – Phases Generic

Rurban Hospice Palliative Care Program PHASES OF PROGRAM DEVELOPMENT



Appendix E – Phases of Program Development

Rurban Hospice Palliative Care Program PHASES OF PROGRAM DEVELOPMENT



Appendix F - Steering Committee Terms of Reference

Purpose:

The purpose of the Rurban Project is to develop a Primary Health Approach to hospice palliative care

Outcome:

The outcome is a Rurban Palliative Care Model and process, which can be adopted by other Regions in Western Canada. The sponsor of the project is Pallium has provided \$15,000 for the project. The outcome of the project is due April 1, 2006.

Organizational Structure:

The Rurban Palliative Care Initiative is championed in partnership between the Regina Qu'Appelle Health Region and Pallium Inc.. The steering committee will be chaired by the Director of Palliative Care Services with dual reporting to the Executive Director of Family Medicine, Home Care and Palliative Care and the Executive Director of Rural Health Facilities.

An advisory committee will provide ongoing guidance to the Steering committee. The Advisory Committee will consist of:

- Executive Director of Family Medicine, Home Care and Palliative Care and the Executive Director of Rural Health Facilities
- Director of Palliative Care Services
- Director of Strategic Corporate Development
- Dr. S. McMillian & Dr. L. Clein Medical Director

The Steering Committee is an adhoc committee formed to provide guidance to the project and facilitate the completion of the project plan.

The Steering Committee will consist of:

- Members of both Rural and Urban Palliative Care Service Delivery Teams & Management
- First Nations and/or Metis Representative

Roles and Responsibility of Steering Committee:

The Steering Committee will be responsible for the following.

To be...

- Champions and advocates for the Rurban Palliative Care initiative
- Create and understanding of the philosophy and principles of the Rurban Palliative Care Initiative.
- Create a common vision for Rurban Palliative Care Initiative using the principles of community collaboration
- Direct the development and progress of the initiative and provide guidance to the project leader.
- Develop and "model or framework" for Rurban Palliative Care Initiative.
- Develop goals, objectives and a strategy for the implementation of the Rurban Palliative Care Initiative in consultation with key stakeholders
- Develop indicators to evaluate the outcomes and success of the initiative.
- Assist with the assessment, data collection and analysis of what currently exists (the current state) and completing the environmental scan.

Principles of Operation for the Steering Committee:

- Holistic care for clients and families
- Client centred and community development approach
- Open, honest communication
- Respect for all
- Common vision and goals (no hidden agendas)
- Culturally aware and sensitive (listen to those who have been there)
- Team approach
- Best practice standards, ie. ethics , education
- Continuum of care for Rural and Urban
- Decisions by consensus

Meetings:

Meetings will be called by the Chair-person as required to necessitate the completion of the project plan.

Appendix G – Family Interview Guide

THE RQHR RURBAN PALLIATIVE CARE PROJECT

For Hospice Palliative Care in rural areas

Family Interview Guide

Family Name: _____

1. Describe your experience with hospice and palliative care...(your recent end life experience). What was your experience, who was involved, how did it unfold?

From that experience, what was most meaning for you and for your family?

Recalling that experience...what did you or your family value most in this end of life experience?

2. Thinking back on your experience we would like to have a conversation on some of your likes and wishes for others in your community receiving palliatives services in the future related to some specific areas.

Care/Service	Likes	Wishes
End of Life Care		
Continuity of Care between the team of service providers		
Family Needs		
Spiritual Needs		
Pain and Symptom Control		
Community Support		

3. Is there anything else you would like to tell us about your experience that we have not talked about that you feel is important for us to consider?

Appendix H – Session Agenda & Interview Guide

The RQHR Rurban Palliative Care Project

COMMUNITY CONSULTATION

AGENDA

Time	CONTENT
15 Minutes	Introduction <ul style="list-style-type: none">▪ Welcome and Introductions▪ Outcomes▪ Setting the Context
30 Minutes	Sharing Positive Experiences-Discovering the Best of End of Life Care <ul style="list-style-type: none">▪ Partner Interviews
45 Minutes	Meaning Experience and Value Identification <ul style="list-style-type: none">▪ Sharing of experiences within the group and selecting meaningful experiences and values▪ Themes of experiences and values
30 Minutes	Shared Meaning of End Life Experiences <ul style="list-style-type: none">▪ Likes and Wishes conversation
15 Minutes	Next Steps <ul style="list-style-type: none">▪ Where do we go from here▪ Keeping Involved and in touch with the process
	Closing

The RQHR Rurban Palliative Care Project

Creating a Meaningful End of Life Experience **Interview Guide**

INTERVIEWER:

Your task is to interview another person and draw out their story so that they relate not only the facts but also the feelings, the energy of their story. There are no right or wrong answers to these questions!

You have about 15 minutes to interview your partner.

1. As you look back over your experience with end of life care think about a time that stands out for you as a positive experience – a time when you felt engaged, fully present to those around you, compassionate and proud of the contribution that was being made.

Please share a story about that time. ***Who was involved, what did you and others do? What made this a meaningful experience?***

2. **Valuing:** Without being humble.....***what did you value in your contribution and the contribution of others in this situation?***

3. **Images of the Future:** Imagine yourself in 2010. You discover that many small and large miracles have happened and that rural palliative care has changed in ways you would most like to see – for the clients and their families, for the service providers and the community. You are happy with what you see and you have been instrumental in creating the positive change.

Share highlights of what you see: *what do you see happening that is new, better, healthy and good? What do you see in your vision of a vibrant, meaningful hospice palliative care service in your area?*

4. **Moving to Action:** As you look at your role in helping to create meaningful end of life experiences for rural residence *what is a small step that might have an impact on the overall success of future rural urban palliative care.*

Physician Interview Guide

Discussion via conference call February 10, 2006

1. In talking with other members, folks had talk about a meaningful end of life experience.... In thinking back over the palliative care patients you have had...what would say made for meaning end of life experience for the patient and the family.
1. Within your community or care facility what has contributed to this... What supports and services do you have?
2. What has been difficult or hard in providing palliative care to your patients and their families?
4. Anything else we need consider as we continue to develop the Rurban palliative care model?

Appendix I - Demographics & Baseline Data

INFORMATION	REGINA HEALTH DISTRICT	PIPESTONE	TOUCHWOOD QU'APPELLE
Population (general)	246,877 (2005 stat) (*)	19,836(1999 stats)	14,780
First Nation Population	21,981 (Registered – 2005 Stat) (*)	2672(1999 stats)	5,500 on reserve
Area (km2)		Approx 10,000 km2	
Palliative Care Data <ul style="list-style-type: none"> ▪ Referrals (Annually) ▪ Deaths (Annually) ▪ Palliative patients (annually) ▪ Home Deaths 	(2005 Stats) <ul style="list-style-type: none"> ▪ Referrals – SWADD PC Home = 355 ▪ Admissions – PC Unit = 365 ▪ Deaths – PC Unit = 372 ▪ Regina Grace Hospice = 80 ▪ Home Deaths = 81 	<ul style="list-style-type: none"> ▪ Home Care ▪ 8 ▪ 7 ▪ 8...home deaths 3 	<ul style="list-style-type: none"> ▪ Home Care ▪ 12 ▪ 6 ▪ 12...Home Deaths 0
Access to Home Care (days per week, 24/7)	<ul style="list-style-type: none"> ▪ 24/7 	14 hours/7 days week	<ul style="list-style-type: none"> ▪ Fort Qu' Appelle– 7 days/week ▪ Balcarres,Lestock,Raymore – 5 days/week – 8 hour coverage, 4 hours on weekends, 24 hour on call.
Home Nursing Availability	<ul style="list-style-type: none"> ▪ 24/7 	<ul style="list-style-type: none"> ▪ Monday-Friday: Moosomin, Indian Head, White Wood ▪ 2 days/wk Broadview, Rocanville, Monmartre ▪ 1 day/wk Wolsely 	<ul style="list-style-type: none"> ▪ Yes – Fort Qu' Appelle, Balcarres, Lestock
Access to Community Facility for Hospice Palliative Care	<ul style="list-style-type: none"> ▪ Direct Admit from PCS Team ▪ 10 Beds – Regina Wascana Grace Hospice ▪ WRC & Sunset – as assessed 	Yes-Moosomin, Indian Head, Wolseley, Grenfell, Broadview, White Wood, Monmartre	Yes – Fort Qu' Appelle, Balcarres, Lestock, Raymore
24-hour Respite	<ul style="list-style-type: none"> ▪ Yes – if assessed 	Yes-Montmartre, Indian Head, Wolseley, Grenfell, Broadview, Wolseley	Yes
Medication Coverage (pharmacare etc)	<ul style="list-style-type: none"> ▪ 24 Hours 	Yes	Consult through Regina
Palliative Nurse Consultation	<ul style="list-style-type: none"> ▪ 24 hours 	Consult through Regina (Inconsistent and limited)	Consult through Regina
Palliative Physician Consultation	<ul style="list-style-type: none"> ▪ 24 hours 	Inconsistent/Limited –have utilized resources in Regina-varies from physician to physician	None
Palliative Care volunteers	<ul style="list-style-type: none"> ▪ 24 hours 	Moosomin only (Hope Program)	None
Bereavement Services	<ul style="list-style-type: none"> ▪ Winter 2006 Bereavement Support ▪ Caring Hearts Camp 	None	None
Other Palliative Supports e.g. social work, therapies	<ul style="list-style-type: none"> ▪ See Attached Program <ul style="list-style-type: none"> ○ Palliative Care Services 	Access Community Therapists Limited access to social work, mental health	Community therapists, NO social workers.

(*) – stats derived from Sask Health Web Site (www.health.gov.sk.ca/2005 covered Population
 - Aboriginal stat www.health.gov.sk.ca/mc_dp_covpop_2005/csu/covpop-plan_17_regd_rha-ageyrs_2005.cv

Palliative Care Services

SWADD: The System Wide Admission/Discharge Department Palliative Care Coordinators assess, coordinate, communicate and implement a continuum of care for clients and families of Palliative Care Services.

Palliative Home Care: The Palliative Home Care team provides management of pain and symptoms, ongoing assessment, personal care, a liaison between client and doctor, and professional/interdisciplinary support to clients and families in their own home setting.

Palliative Care Unit: Located at the Pasqua Hospital, the nine-bed palliative acute care unit provides short term hospitalization for patients needing management of pain and symptoms such as nausea; anxiety and restlessness. The environment of the Palliative Care Unit is one of serenity and comfort, designed to meet the needs of the individual, family and friends.

Regina Wascana Grace Hospice: Hospice provides a home-like environment with stimulating recreational programs such as entertainment, games, music and outings for clients who cannot be cared for at home and require longer term supportive care.

Medical Care: The primary medical care giver to palliative care clients is the family physician. However, consultative pain and physical symptom support is provided by the Palliative Care Medical Director in the acute care facility, the long term care special care home and at the residence.

Social Work: Care is provided to assist patients and families to cope with the emotional, physical, social and financial implications of a life-limiting illness. The client may feel overwhelmed with fears and uncertainty. The Social Worker can assist not only in the anticipation of a future possible loss, but also with reactions to losses being experienced such as losses of health, mobility and future plans.

Volunteer Program: The Volunteer Program consists of approximately 65 trained volunteers who provide sensitive and skilled care in the setting most appropriate - in the acute care facility, the long term care special care home or at the residence. There is no charge to the client or family for volunteer services.

Spiritual Care: When facing a life-limiting illness, clients may be thinking about such things as the meaning of life, hope, fear, guilt, abandonment or faith. And, whether or not they are religious, they may want to experience a greater measure of peace, contentment and harmony as the end of life approaches. The Chaplain is available to assist no matter what religious background or philosophy of life.

Occupational Therapy: Occupational therapy will help make the most of a client's capacity and independence in the areas of self-care (activities of daily living), work (making a productive contribution to life - domestic duties, employment or volunteer activities) and leisure (activities of enjoyment and renewal).

Music Therapy: Music has the capacity to stimulate memories, modify mood, soothe pain, address fears, express feelings, calm and relax. Music as a therapeutic tool addresses spiritual, physical, and psychosocial needs. Music Therapy is available to assist clients and families coping with a life-threatening illness.

Bereavement Care: When facing a life-limiting illness, Palliative Care Services offers a variety of care to help clients and families understand more about imminent loss, grief and bereavement. This care includes resource materials, bereavement support groups for adults, teens and children, or individual counselling. Adult bereavement support groups are conducted by volunteer professionals three times a year. Following the five sessions, other support groups are offered. To meet the grieving needs of children and teens, the Childhood/Teen Grief Support Group meets twice a year.

Resource Centre: A variety of current books, journals, magazines, videos and tapes on palliative care topics are available for loan. Information is relevant to all ages, including children.

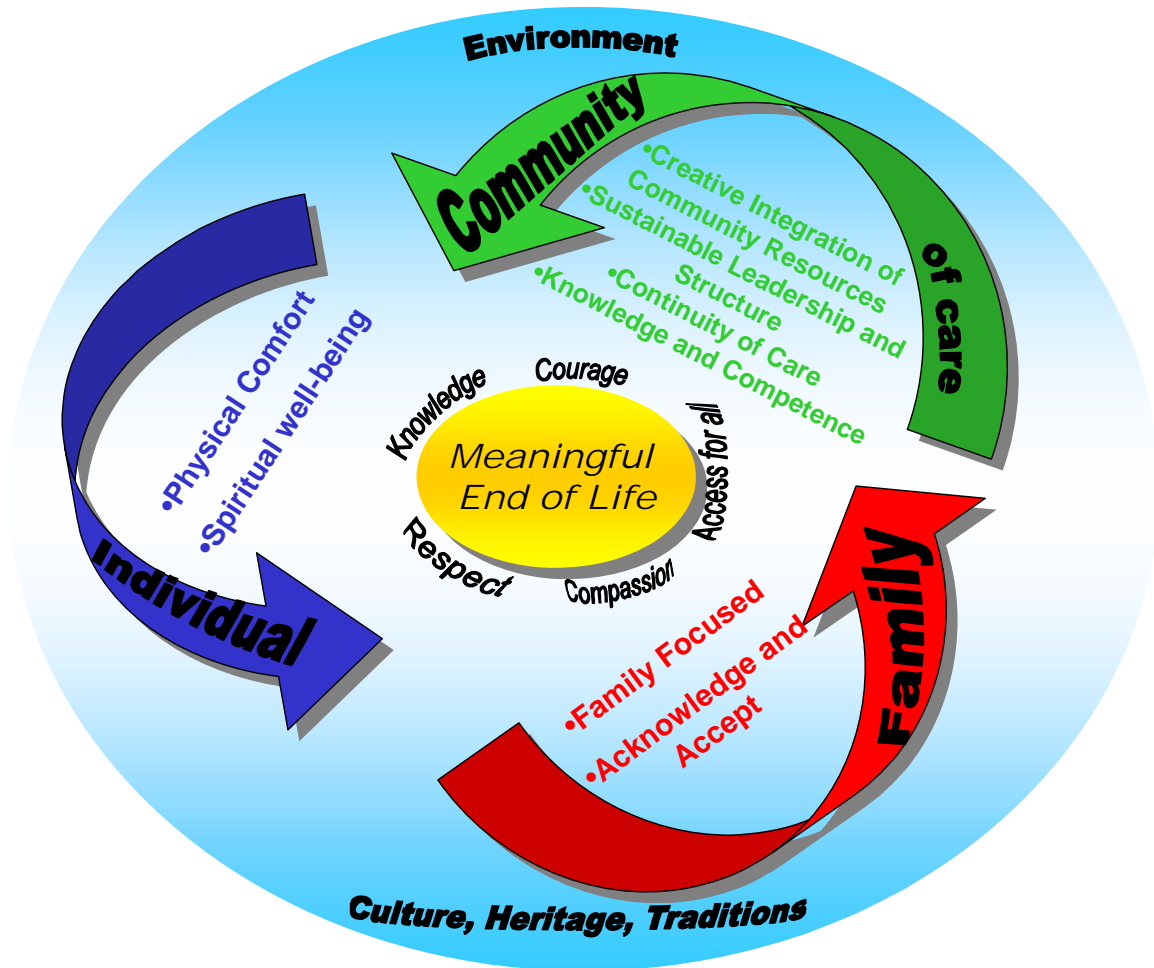
For more information, please call: Phone 766-2665 or 766-2674



Printed May 2005

Ceac #193

Appendix J – Rurban Model: RQHR



Appendix K – Components of Care: Provocative Statements

The Components of Care are written as *Provocative Statements*. Together they describe what contributes to a meaningful end of life experience and how it is supported. [See Appendix A]

Individual

Physical Comfort

The patient is comfortable - physical pain and symptoms are managed to enable meaningful interactions with loved ones until the time of death. The effective management of advanced pain and symptoms is provided through the use of appropriate therapeutic methods, equipment and material resources.

- The environment of care is safe, comfortable and peaceful in the eyes of the patient, family and community of care.
- The clinical team provides competent assessment and treatment of the patient's pain and physical symptoms skillfully delivering appropriate and timely treatment options at or close to home.
- The patient has access to competent, holistic pain management, both pharmaceutical and non-pharmaceutical.
- The patient, family and community of care have timely access to equipment enabling independence, safety and the ability to be stay in the comfort of one's home.
- Families are confident in caring for their loved one within the setting they choose, guided by members of the community of care and support with information, education and adequate equipment.

Spiritual Well-being

A holistic approach addresses spiritual, emotional, social and physical pain. Care providers assist the patient to discover opportunities for growth at the end of life. The patient and family is supported in their suffering in a way that maintains personal integrity, is meaningful for them and is sensitive to their cultural traditions.

- Patients are supported in telling their stories – to speak of their sense of loss and of what has given their lives meaning.
- The patient and family have the opportunity to talk about the meaning of the illness, life issues and the experience of dying.
- Patients have the opportunity to create and leave a legacy for those they love.
- The individual's beliefs and practices related to death and dying are respected and care provided that is compatible with these beliefs. Cultural traditions and ceremonies are honored as appropriate.
- Discretionary practices allow the patient to die peacefully without clinical intervention and to 'bend the rules' to accommodate the patient's last wishes.

Family

Family Focused

The death of a loved one is a very personal experience. Families are encouraged and supported in deciding how the care of their loved one will unfold – leading the dance where they can and drawing on the expertise, strength of the care providers as they require. Families:

- Decide how to honor the end of life process within their own tradition of practices and rituals, and how to make decisions as a family.
- Receive honest & complete knowledge, as appropriate, regarding the options provided by the health care system and their rights and responsibilities as an integral part of the care team.
- Spend time together in ways that are most meaningful e.g. enabling family members to sleep with or close to their loved ones, eating together, etc.
- Have access to information and the guidance they require to make practical decisions to ensure the family's affairs are in order (financial, legal, etc.)
- Are encouraged to draw on their own strengths and resources and are supported in overcoming inhibitions they may have in providing care for their loved one.
- Find peace and the opportunity for reconciliation as a family within their belief system.
- Are comforted with the many 'little extras' provided by the community of care e.g. lunches, flowers, running errands, childcare, etc.

Acknowledge and Accept

Dying is an integral and fundamentally human aspect of living. The acknowledgement and acceptance of death, although difficult, can bring meaning and a profound sense of being alive in the moment, for the patient, family and caregivers.

- Guidance and information allows patients and families to anticipate and mentally prepare for each phase of the experience.
- Mentally competent patients participate in decision making about how the remainder of their life is spent (e.g. location, traditions, compassionate terminal care designation or do not resuscitate).
- The comfort and capacity of care givers to support the patient are recognized and respected.
- Those left behind are supported in their grief and mourning and in the adjustment to life without their loved one through bereavement support.
- Appropriate support is provided for those who have cared for the patient and family.

Community of Care

Knowledge and Competence

The broader community of care has the skills, knowledge and capacity to support end of life.

- Teams are made up of family members, health care professionals, physicians, volunteers, community members, spiritual and religious counsel.
- Interdisciplinary teams develop their competencies and skill levels based on national norms and practices in collaborative learning environments.
- Members of the Community of Care are confident in dealing with end of life patients and their families as a result of ongoing education and access to expert support.
- The community of care readily accesses specialized expertise regarding pain management (physical, psychosocial and spiritual) and symptom management throughout the disease trajectory.
- Families have the capacity and guidance enabling them to take an active role in the care of their loved one with confidence.
- Bereavement care within the local communities is developing and is strengthened by its linkages with the Bereavement Centre of Excellence.
- Innovative ways are used to exchange knowledge, build skills and transfer skills where appropriate ie: practice site exchanges, teleconferencing, telehealth, healthlines, and online collaboration (e-village).

Continuity of Care

Access and continuity of care is enhanced in rural areas through flexible use of existing services, and effective coordination.

- The community of care is included in the discharge planning of palliative patients prior to discharge from acute care (referral).
- Patients and families understand their options for palliative care at the time of diagnosis or discharge. The Community of Care recognizes the capacity of the family to utilize these options, recommending only those that are appropriate and accepting the family's decisions.
- Continuity of care is provided for patients through a trusted care team where there is rapport and consistent approach to care has been established.
- Care providers readily communicate patient information facilitating continuity of care and easing the burden on families and patients.
- Hospice Palliative Care is coordinated throughout the Region ensuring effective case management and strong linkages between services.
- Patients move easily between the various care environments enabled by the appropriate supports i.e. transportation, health record etc., for the provision of seamless care.
- Flexible options are available to meet the needs of the patient and family such as: access to service around the clock as required; bed availability within the home community; and, system supports for consistent care providers.
- Patients and families have a single point of access to inquire about and obtain palliative care information and services.

Sustainable Leadership and Structure

The RQHR Ruban Hospice Palliative Care Initiative is sustained through a strong shared leadership between RQHR and the Community of Care. This strong alliance ensures each palliative individual and family has an opportunity for a meaningful and supported “*end of life experience*”.

- Strong collaboration, teamwork and relationship building amongst the Community of Care is ongoing.
- Solid direction for the initiative aligned with the strategic framework for RQHR with clear lines of authority and responsibility.
- Physicians are strongly engaged with the “Rurban End of Life philosophy” and are innovating ways to address the palliative clients’ unique needs within their community.
- Flexible boundaries enable palliative patients to die within their community, surrounded by friends and family.
- Equipment and other material resources required for patient comfort have been determined and pooled together within the Region’s communities enabling community sharing and timely access for patients.
- Passionate experienced teams of service providers and volunteers are working collaboratively within the communities, building upon each other’s strengths, in creative ways to meet the needs of the patients.
- The community of care is supported with excellent education, flexible allocation of resources, safety and emotional/psychological supports to thrive and flourish in a challenging but extremely rewarding palliative care environment.
- Funding sources to support and sustain the Rurban Hospice Palliative Care Initiative are secured including a physician remuneration framework.

Creative Integration of Community Resources

The integrity of communities is preserved while capacity is enhanced through greater integration of resources between the communities, rural and urban. Independence and interdependence are fostered.

- The model of care integrates the skills, resources and unique approaches within the communities to strengthen the overall capacity of HPC throughout the Region.
- The unique treasures of communities are embraced in supporting the end of life experience for their members such as service organizations, fundraising activities, and cultural resources.
- An inventory for the sharing physical resources has been established enabling timely access to needed equipment and resources throughout the Region.
- Equitable hospice palliative care is available for all regardless of their social economic status, family background or their relationship with the community.

Appendix L – Strategic Directions

1. Strategic Direction: Establish a culture that supports Hospice Palliative Care

Principles of hospice palliative care that acknowledges death as an integral part of life are integrated into all aspects of hospice palliative care practice and care delivery.

Goal(s)

Define the principles of Hospice Palliative Care that acknowledges death as part of the cycle of life:

- *HPC is centred on the dying person, his or her family and the individual's view/perception of their dying (abandonment of hope for a cure, and often the acceptance of the inevitable death)*
- *Acknowledging everyone (patient, family, CoC) experiences and accepts dying and death differently and in varying degrees*

Create a process to integrate the principles into all aspects of practice.

2. Strategic Direction: Advance Knowledge through Education

All levels of the Community of Care have the knowledge and capacity (reflective of the appropriate scope of practice of the CoC) of the philosophy, principles and the standards practices of effective hospice palliative care.

Goals

Enhance knowledge and capacity of all levels of the Community of Care regarding the philosophy, principles and the standard practices of effective Hospice Palliative Care (reflective of appropriate scope of practice of the CoC).

Create structures that support team learning and communication and build interdisciplinary team relationships.

Possible Actions

- Collaboratively develop and conduct education and training in various geographical areas, to explore:
 - Holistic assessment for nurses, physicians and interdisciplinary teams
 - Palliative pain symptom management
 - Comfort, safety and independence issues
 - Access to/understanding of PCS Guidelines
- Provide training for team members in identifying & understanding the spiritual and religious needs, resources of clients and appropriate spiritual care intervention.

3. Strategic Direction: Strengthen and Preserve the Integrity of the Family

All processes of providing care such as information sharing, decision-making, care plan development and care delivery are developed and implemented in consideration of the unique dynamics within each family.

Goals

Develop a process of providing care, information sharing, decision-making, care plan development and care delivery, as it relates to family dynamics.

Possible Actions

- Develop a methodology to assess family capacity and understanding of options
- Create HP/EOLC environments/services respective of personal values, beliefs, practices and strengths.
- Enable families to be informed about his/her illness, available therapeutic options throughout their illness and bereavement experience.
- Enhance the knowledge of patients and families around HPC options.
- Build, strengthen and maintain familial relationships.

4. Strategic Direction: Expand Innovation and the use of Technology

Innovative methodologies are used for knowledge exchange, skill development and to link the CoC across geographic distances i.e. practice site exchanges, the use of healthlines, teleconferencing etc.

Goals

Develop and expand upon the use of methodology for knowledge exchange, skill development and linking the CoC between geographic distances. (I.e. practice site exchanges, health-lines, teleconferencing etc.)

Encourage participation of community spiritual and religious care givers in program of clinical training.

- eVillage posting of Clinical Pastoral Education in HPC.
- eVillage posting of HPC Spiritual Care Provider Resource Package
- Tele-health learning opportunities.

5. Strategic Direction: Enhance Access and Coordination

All RQHR citizens have access to hospice palliative care and the necessary community supports, regardless of location, culture and social economic status.

Goals

Establish processes to enable all RQHR citizens access to hospice palliative care and the necessary community supports regardless of their location, culture and social economic status.

Build processes to facilitate linkages between the urban and rural care environments ensuring timely transfer palliative patients and necessary information.

Possible Actions

- Create a process to include the community of care for D/C planning of palliative clients.
- Develop palliative care pathways and communication processes to ensure consistent approach and a seamless continuum of care.
- Promote and utilize Palliative Tele-health Nursing Guidelines.

6. Strategic Direction: Embed a Shared Leadership Model

A shared leadership model with the Community of Care encourages creativity in resource allocation and builds strong collaborative relationships within the Community of Care.

Goals

Develop a shared leadership model with the Community of Care that encourages creativity in resource allocation to best support delivery of care within communities.

Establish an ongoing commitment to building and sustaining strong collaborative relationships within the community of care.

7. Strategic Direction: Establish Resource Management Processes

The RQHR has established a process for the pooling and sharing of resources, skills, unique approaches to service delivery and physical resources.

Goals

Develop an approach for pooling and sharing resources (skills, unique approaches, and physical resources).

Develop processes to determine and allocate resources to support delivery of flexible creative services.

Possible Actions

- Create an inventory of resources and capabilities available to support end of life within the community, and amongst communities (e.g. service groups, organizations, professionals etc.).
- Provide resources, human and fiscal, required to function and provide care in a safe, ethical, responsive and compassionate manner i.e. family compassionate leave.

8. Strategic Direction: Honor Culture, Heritage and Tradition

Appropriate supports for palliative patients and families in the RQHR are in place for Aboriginal people and people of other cultural and ethnic groups.

Goals

In partnership with (aboriginal & other cultural/ethnic organizations) develop appropriate supports for palliative patients and families in RQHR.

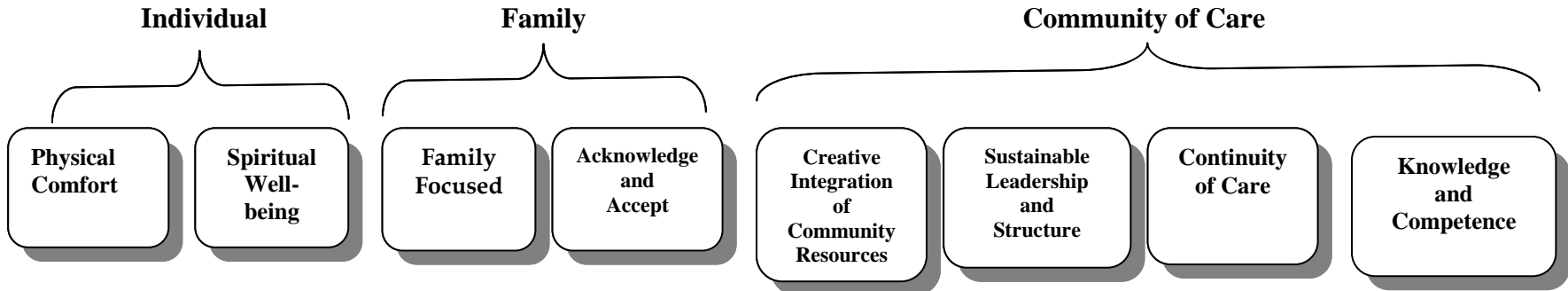
Explore the creation of a parallel process to develop HP/EOLC for First Nation and Aboriginal people in RQHR.

Appendix M - RQHR Strategic Framework

What a Rurban Palliative Care Program will look like.

Vision: Meaningful End of Life Experience
Values: Respect, Compassion, Courage, Access for all, Knowledge

Components of Care



Strategic Directions

Provocative Statements for each Component defining success
(How we will know when we get there)

Strategic Directions

- Establish a culture that supports Hospice Palliative Care
- Advance Knowledge through Education
- Expand Innovation and the use of Technology
- Enhance Access and Coordination
- Embed a Shared Leadership Model
- Establish Resource Management Processes
- Strengthen and Preserve the Integrity of the Family
- Honor Cultural, Heritage and Tradition

Strategic Plan

