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White Paper: Building a Continuum of End of Life Care in Whatcom County: Invest in Community-Based Palliative Care

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Building a Continuum of End of Life Care in Whatcom County: Invest in Community-Based Palliative Care

October 2014

Prepared by Bree Johnston, MD, MPH

Overview

Whatcom County has established significant specialty palliative care services, including a strong Hospice Program, an Inpatient Palliative Care Consultation Service, and a low volume outpatient palliative care clinic for patients with advanced cancer based in the PeaceHealth Comprehensive Cancer Center. Family Care Network has also started a low volume nurse practitioner based home care program for vulnerable patients. However, the vast majority of palliative care is provided by generalist providers outside of formal palliative care or hospice programs.

Substantial gaps in specialty palliative care services exist throughout the care continuum in Whatcom County. Specialty and primary care providers cite the need for specialty palliative care services for homebound patients and patients with advanced illness. Nursing home and assisted living staff also cite the need for advanced palliative care consultations for their complex patients. In summary, there is a strong unmet need for outpatient and home-based palliative care services in Whatcom County.

It is widely recognized that palliative care improves quality of life for patients with advanced illness and their families, reduces costs, and advances the Triple Aim. The literature supporting the value of palliative care will not be reviewed in this document.

Goal

To explore gaps in palliative care services in Whatcom County and to propose programmatic approaches to filling those gaps. This report will focus on specialty palliative care programs in Whatcom County, and will not address other aspects of palliative care (e.g., education, advance directives, culture).

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This White Paper is one of five working papers, each of which covers a different content area and was developed by a separate Work Group. These papers were used to inform the development of the Blueprint for Community Excellence at End of Life. As such, this White Paper is not to be viewed as a formal or standalone document, but rather as supplemental and expanded material for those who may be interested in additional information and content in a specific area. If there are any discrepancies between this paper and the Blueprint, the Blueprint represents the final decision of the Steering Committee.

WHITE PAPER

Background: Palliative Care Services in Whatcom County

Whatcom Hospice: Whatcom County has a strong hospice program with excellent community support. According to some data (see appendix A), Whatcom Hospice serves over half of patients dying in Whatcom County. Whatcom Hospice usually has a census of between 100 and 200 patients, and serves about 800 patients a year. Hospice House served approximately 1,000 patients in its first two years of operation. Despite the excellent services offered, hospice personnel cite frustration that referrals often come to them late in the course of illness, and they often feel that opportunities to assist patients in the dying process are limited by these late referrals.

PeaceHealth Palliative Care Service: The inpatient palliative care service was started in the fall of 2011 with a generous grant from the RiverStyx Foundation, and a commitment by PeaceHealth to continue program support after the initial two year grant-funded period. The service is staffed by 1.0 MD FTE, 1.0 RN, 0.5 MSW, 0.5 chaplain (in-kind), and 0.5 administrative support staff. The service operates only during traditional weekday business hours. In the first two years, the service consulted on about 500 patients per year, with the trend for consults increasing over time.

In January of 2014, the Palliative Care Team started a small biweekly outpatient clinic in the cancer center for patients with advanced cancer. The palliative care service occasionally follows patients on an outpatient basis.

The palliative care team cites frustration with late referrals and an inability to have maximal impact because of limited hours and lack of an outpatient service.

Skilled Nursing Homes: There are nine skilled nursing facilities in Whatcom County. According to 2013 data, about 18-28% of Whatcom County deaths occur in nursing facilities. Based on a recent survey (see Appendix B), nursing home personnel estimate that between 25-90% of their residents are within the last two years of life. Nursing home staff state that strengths in end of life care include symptom control, treating patients with dignity, and counseling patients. However, they cite challenges to providing end of life care as including lack of backup from physician/provider staff, lack of time to spend with patients and families, and lack of availability of a palliative care team to assist. Two of the three SNFs who responded to the survey listed their top priority as adding a skilled nursing facility-based palliative care program. It is unclear how generalizable these answers are.

Assisted Living Facilities: There are about 13 assisted living facilities in Whatcom County; if adult family homes are included under this label, it is an even large number. Assisted living facilities are extremely heterogeneous in terms of size, population served, and percentage of clients in the last two years of life. Three assisted living facilities responded to the survey (see Appendix B). They cite challenges in end of life care as including lack of training in symptom management, and lack of a community palliative care program to assist. Assisted living facilities listed priorities as including availability of a home-based palliative care program, better training, and increased availability of Death with Dignity. It is unclear how generalizable these answers are.

FCN Care Support Team: FCN has started a small home care program staffed by two nurse practitioners who provide home-based supportive care for patients with advanced illness, working closely with their primary FCN providers. The service is currently only available two days per week. The demand for the program is currently unknown.

Primary Care Providers: Ten outpatient providers responded to the survey (7 clinics, 1 tribal center, 1 private practice, and 1 cancer center). The two most commonly cited challenges were lack of time to spend with patients and their families and lack of availability of a palliative care team. The highest priority for outpatient clinics was the development of a home based palliative care program, although other services were also cited as priorities.

Home Health Services: There are two skilled home health service agencies in Whatcom County, serving about 800 patients annually (according to the self-report survey data in Appendix B; this was not otherwise verified). Personnel of these agencies estimate that about 10% of their patients are in the last two years of life. Challenges mentioned include lack of training on how to talk to patients about end of life care, lack of training in symptom management, and lack of community resources to help with this population. The top priority was listed as being a home-based palliative care program.

Alternative and Complementary Practitioners: There are many acupuncturists, massage therapists, herbalists, naturopaths, chiropractors, and other alternative and complementary practitioners in Whatcom County. Many patients with advanced illness seek care from one or more of these practitioners. Unfortunately, we did not have any responses to our needs assessment survey from this population, so our information is limited and anecdotal in nature. However, it is important to acknowledge that this population of practitioners is an important source of support and palliation among the seriously ill population.

Community Case Management: A number of community case management programs exist for patients with complex/chronic illness. Only one responded to the survey. It is unclear what the priorities for case managers are.

Community Strengths

Community strengths relevant to palliative care include:

- Strong primary care networks
- Availability of services through SeaMar and Interfaith for low income patients
- Robust community of alternative and complementary providers
- Innovative advocacy and patient services through the Whatcom Alliance for Health Advancement (WAHA)
- A well-grounded hospice program including a hospice house with substantial community support
- A fledgling palliative care program

- Presence of the Center for Senior Health, with geriatrics expertise that is provided in an outpatient clinic as well as at some of the community nursing homes
- Solid history of health care innovation through WAHA and others
- Vigorous case management programs
- Three nursing programs, including the WWU RN to BSN program
- A community that is extremely supportive of palliative care (see Culture Task Force White Paper), including The Palliative Care Initiative, the Death Café, engaged philanthropists, and the End of Life Choices Program

Community Weaknesses

Weaknesses identified by survey recipients and by members of the task force include the following:

- Late referral to hospice
- Lack of expertise in community SNFs, assisted living facilities, and adult family homes in providing end of life care (e.g., communication and symptom management)
- Lack of physician/provider backup in community SNFs, assisted living facilities, and adult family homes for end of life care
- Lack of expertise in symptom management and how to conduct end of life discussions among primary care and specialty providers
- Lack of palliative care specialty services for patients who are not hospitalized
- Underutilization of home health services for patients who are homebound

The survey (see appendix B) identifies shortcomings in services, as identified by community providers. Survey respondents cite the following problems in providing high quality palliative care to their clients:

Rank	Shortcoming	Percent of Respondents (Total n = 25)
1 (tie)	Lack of time to spend with patients/families	52% (n = 13)
1 (tie)	Lack of community resources/programs	52% (n = 13)
3	Lack of training in symptom management	32% (n = 8)
4	Lack of availability of trained palliative care team	28% (n = 7)
5 (tie)	Lack of training in discussing end of life care	24% (n = 6)

5 (tie)	Lack of support or backup from physician/provider staff	24% (n = 6)
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In addition, some respondents cite the presence of only one hospital, a Catholic Hospital, as being a community weakness. Some respondents also cite lack of availability of Death with Dignity as being a community weakness.

Recommendation: Invest in Community-Based Palliative Care

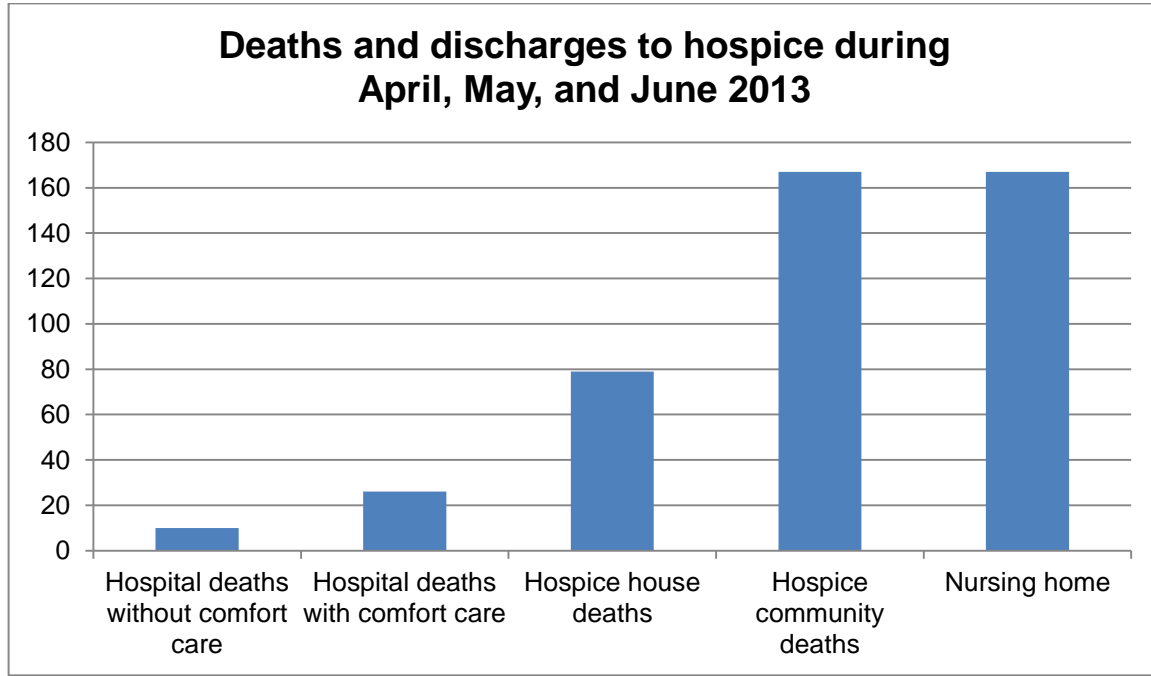
This task force recommends the formation of a group to create a community-based palliative care program in Whatcom County. Our recommendation is to convene a task force that will take 60-90 days to engage prospective funders, gauge the interest of key stakeholders, and will engage in further palliative care program planning. They will be tasked with developing both incremental and comprehensive plans for a community-based palliative care program. The plan will include immediate action calibrated to current resources, a plan for growth, and a framework for sustainability.

Key principles and design elements of the program that we would recommend:

- Include a full interdisciplinary team to provide expert symptom management, emotional, psychosocial, and spiritual support
- Provide coordination with other existing programs, offering wrap-around support, and avoiding redundancy with other services
- Offer care coordination and open discussions of treatment choices
- Enact support so that palliative care can be available across the continuum of care, wherever the patient resides, and when appropriate, alongside other specialty services or in clinics
- Develop support for family and community caregivers in tandem with professional/skilled palliative care services since they are an important part of providing care to patients with advanced illness

APPENDICES

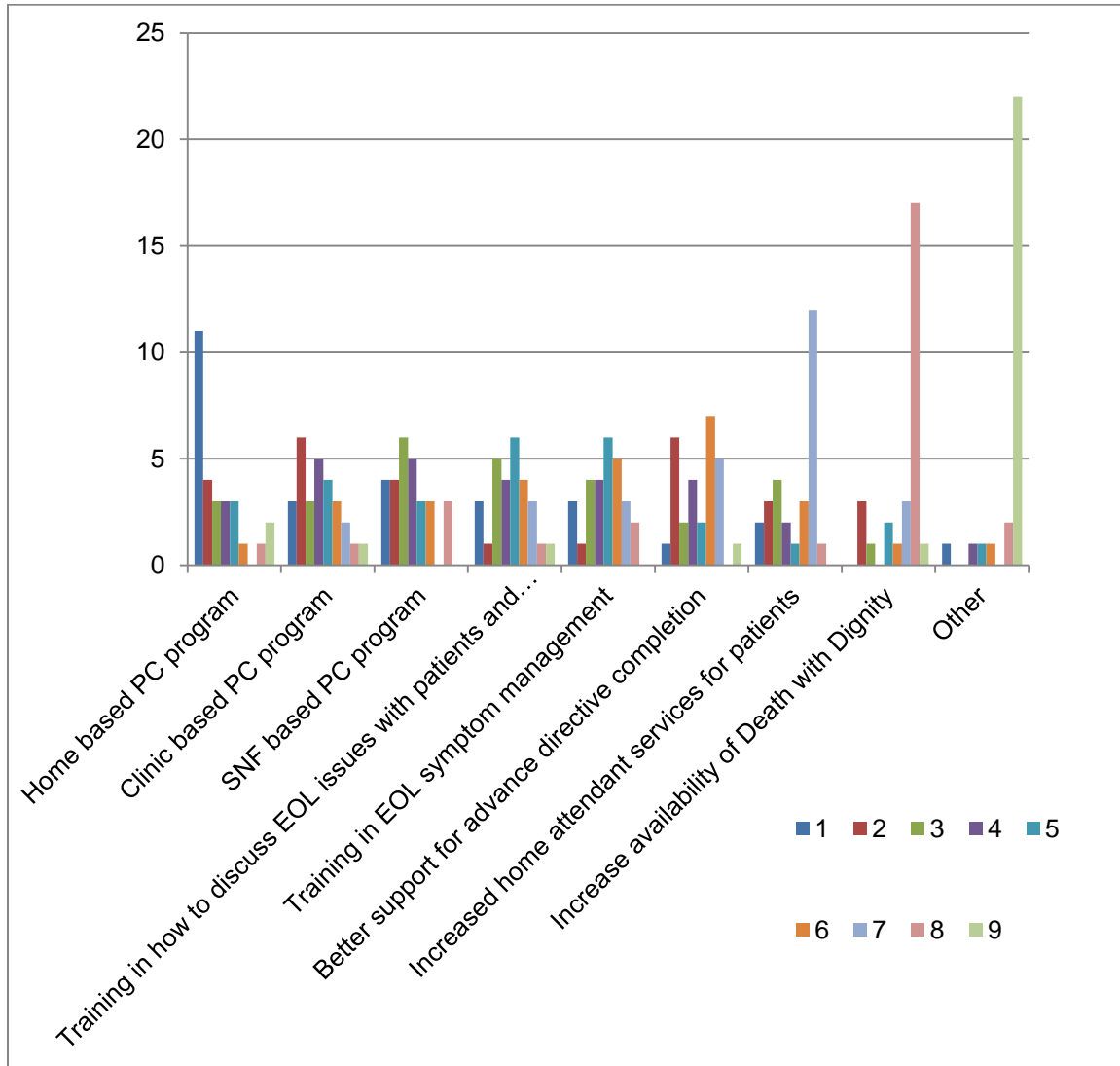
Appendix A: Place of Death in Whatcom County During a Three Month Period in 2013



These data were collected by Bree Johnston using data from the Whatcom County Health Department, nursing homes, Whatcom County Hospice, and PeaceHealth St. Joseph Medical Center. It is not known whether this is representative.

Appendix B: Palliative Care Community Survey Results

The following is the results of question 6 from the survey: If you could add local programs or resources to care for patients in the last 2 years of life, what would they be? Respondents ranked the services from 1 to 9, from most to least important.



Full results can be viewed here:

<https://www.surveymonkey.com/results/SM-QWVVBN8/>

Appendix C: The Life Passages Model

Life Passages (LP) Program, as described by Laura Matthews, Clinical Supervisor

Life Passages clients are typically individuals who have a chronic, debilitating or terminal illness. These patients have significant symptom burdens, emotional, spiritual and practical needs putting them at high risk for hospitalization and readmissions. They have been assessed for Hospice care but psychologically are not ready, do not meet admission criteria, or have been admitted to hospice but stabilized and discharged. They may have a deteriorating medical condition and need symptom management or practical support, may have had 1-2 Emergency Department or Hospital admissions in the last year, or may be receiving curative therapy and be currently involved with Home Health. The LP program provides the missing layer of support for these at risk patients, including earlier access to palliative care, often before a hospitalization becomes necessary.

All LP patients receive advance care planning (ACP), and we have created a comprehensive and effective program that provides for informed healthcare decisions. We are able to increase the patient's participation in decisions regarding their care, treatment, or services before the final days of life and create a complete patient record reflecting their wishes. The LP staff engages patients in conversations, establishes trust, and provides the time needed for ACP discussions. Goals of care are clarified and the idea of end of life is normalized. Studies show that when care options are discussed many people prefer less aggressive care. Their goal is to be comfortable and with family, in their own home surrounded by loved ones. The LP program facilitates these wishes.

One of the roles of the Life Care Coordinators is to assess the psychological and social needs of our clients. Their expertise is especially important given the complex psychosocial issues found at the end of life including caregiving deficits and lack of ACP. These problems pose significant barriers to coordinated care and cannot be solved with medical interventions alone. The team provides clinical coordination and expertise regarding palliative care and acts as a consult for those working with patients and families with end of life symptom burdens. They are able to address the pain and symptom burdens that many people experience, as well as the cultural, emotional, spiritual and functional issues to help improve quality of life.

The LP program depends on volunteers who provide practical help in order to enable the patient to remain at home and independent for as long as possible. The table below provides a summary of volunteer tasks which are identified and planned by the care team to ensure the patient's goals are being followed. They have the experience, training, and expertise needed to provide effective utilization and monitoring of health care resources and provide options in care before a crisis arises. They are able to collaborate with other healthcare professionals and work as a united team to improve transitions of care, increase patient satisfaction, and lessen burdens for patients and family whether their goals are comfort or curative care.

<u>Volunteer Tasks</u>	<u>Hours</u>	<u>% of total visits</u>	<u>Volunteer Tasks</u>	<u>Hours</u>	<u>% of total visits</u>
Transportation	121	32%	Shopping	33	8%
Companion/Respite	355	95%	Life Review	3	1%
Housework	46	12%	Pick up RX	21	6%

MD Appointment	17	5%	Pain	42	11%
Healing Touch	9	3%	Symptoms	106	28%
Emotional Support	104	28%	Other	89	24%
Total Hours:	1,076		Total Visits:		373

As described in LP materials, the following elements of the program are instrumental to its success:

Care delivered by a team: Caring for the seriously ill involves more than just the physical aspect. Therefore, we work as a team that includes a nurse, social workers, physicians, volunteer coordinator and volunteers to meet the full spectrum of patient and family needs.

Coordination of treatment: People with chronic conditions often face many complex issues such as: health insurance, coordinating primary care doctors and specialists, equipment, therapies, rehabilitation facilities, home health, in-home care, and medication. LP Care Coordinators assist with managing the patient's plan for treatment and advocate for the specific and personal needs of each patient.

Addressing emotional and spiritual needs: People challenged by serious illness are often affected by emotions and spiritual crisis associated with loss. Our staff, along with volunteer chaplains, is skilled at listening and able to help individuals express their feelings with the goal of reducing and helping to prevent anxiety and stress that get in the way of living well.

Setting goals of care and advanced planning: LP Care Coordinators, MDs, Nurse practitioners and selected volunteers are trained to facilitate discussions about goals and planning with individuals and families affected by serious illness. LP values education for individuals, families, and healthcare practitioners about the risks and benefits of medical interventions and will document their choices.

MD consults available upon physician request: During visits to patients in their homes, physicians focus on relief from symptoms associated with a patient's illness and provide assistance with understanding difficult treatment choices and what to expect of the disease process, as well as help with understanding options, determining priorities and navigating the healthcare system.

Weekly home visits from volunteers: Patient visits by volunteers are tailored to the needs of individuals and their family. Volunteers provide emotional support and companionship and help lessen isolation.

Telephone wellness check-ins: The condition of people with serious illness often changes and those with serious illness may rapidly decline in function, both physically and mentally. Volunteers call patients to ensure their health is stable and that they are safe

and able to meet their basic needs. If needs are identified, patients and families are directed to the appropriate resource.

Assistance with routine living activities: Volunteers are able to provide practical support by assisting with or finding resources for light housekeeping, meal preparation or yard work. It is often the simple things that can make the biggest difference in quality of life for people with limited function.

Rides to appointments or shopping: As debility increases with serious illness, transportation can become a barrier. LP volunteers are able to take people to appointments, pick up prescriptions, and go shopping.

Help for family caregivers: Our goal is to provide emotional and physical support so that the caregiver's health is not also compromised. Our team is available to help process through the issues that often arise when a loved one is seriously ill.

Community website: A website where educational articles on a wide array of topics are available will be established for each of the communities served by LP. The topics include medical concerns, emotional and spiritual issues, and making decisions. This website was created specifically for those suffering from serious illness to serve as a link to community programs, resources, tips, a monthly newsletter, and even a family blog.

Community and health care professional education: LP provides workshops and associated online training modules for the purpose of educating healthcare providers about ACP with specific attention to the POLST or its equivalent, and facilitates a community-based National Healthcare Decisions day in each region. Conferences and educational opportunities regarding end of life issues will also be provided to promote participation and awareness throughout our communities.

Trained staff specialized to deliver LP services: LP hires individuals who meet high professional standards and are gentle and compassionate. LP provides special training for working with the seriously ill and family.

LP referrals: Referrals come from patients and families, physicians, nurse practitioners, clinical coordinators, care managers, discharge planners and social workers, family, friends, and the website. Program brochures are available in waiting rooms throughout the local hospital, clinics, and medical offices.

LP works across the care continuum and has been successful in addressing these issues:

- High utilization of hospital/emergency room services at end of life- LP has reducing ED visits and hospitalizations by 50%; once patient have transitioned to hospice, this reduction rate increases to 98%
- Lack of congruence of medical treatment with patient preferences- 100% of LP patients receive ACP and discussions about goals of care

- Late referrals to hospice care- Over half of all patients served by LP transition to hospice and have longer than average lengths of stay on hospice
- Providing the needed resources that allow patients to remain at home and independent for as long as possible

WAHA is a 501(c)(3) nonprofit organization with a mission *to connect people to health care and to facilitate transformation of the current system into one that improves health, reduces costs, and improves the experience of care.* The WAHA Leadership Board includes consumers and community leaders from the nonprofit, business, and governmental sectors, as well as many local healthcare organizations.

If you have questions or comments regarding this report, please contact Mary Ann Percy at mpercy@hinet.org or 360-788-6526.



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