Experience of care during the end of life: A population-based Mortality Follow Back Study

In 2008, Dr Fred Burge’s population-based Mortality Follow Back Study received a four year operating grant from the Canadian Institutes of Health Research (CIHR). The study examines end of life care experiences among adults in Nova Scotia (NS), and identifies unmet needs, unfulfilled wishes and satisfaction with end of life care using a population-based approach.

Improving care at the end of life is continually important to Nova Scotians and Canadians; however, obtaining information prospectively from dying persons can be difficult. Identifying who is terminally ill remains challenging and factors, such as missing data due to poor function and cognition as well as wanting to avoid burdening the very ill, prevent a complete understanding of the individuals’ care preferences and satisfaction at end of life.

Gauging end of life experiences can be examined from the family’s perspective using a ‘mortality follow back survey’ approach. Mortality follow back surveys have been used internationally (UK, USA, Italy) and are designed to describe the events around death.

Knowledge about health service utilization at end of life among cancer patients in Nova Scotia continues to improve. However, variations in service use by population characteristics have been identified: e.g. elderly using less specialized palliative care and males being more likely to die in the hospital. Whether these inequalities in utilization were due to patient need or preference for care was questioned. If they were due to need and not preference than these inequalities would in-fact be inequities.

Prior to this Study there was no information on patient need or care preferences (wishes) at the end of life in population-based data and there was little knowledge of service use among people dying of diseases other than cancer.

The Mortality Follow Back Study seeks to fill information gaps in the study of end of life care in NS. This includes an estimation (or tentative definition) of ‘need’, data on decision-making and choices, and inclusion of deaths due to other chronic diseases. It will estimate the prevalence of unmet needs, if decedent care wishes were fulfilled, and the satisfaction of care received. Associations between age, sex, and location of care are also examined.

The follow back survey is being administered by telephone and uses the ‘after-death bereaved family member interview’ survey instrument adapted for Canadian use.1 Death certificate informants of Nova Scotian adults (18+ years at death) are being contacted by Nova Scotia Vital Statistics and those interested in participating contact the researchers directly. Invitations to participate are mailed in waves, every four months to ensure death dates occur four to eight months prior to contact.

This Study is providing the first Canadian population-based estimates of patient need and care preferences at end of life. It begins the examination of inequities in utilization and outcome for varying groups. It is designed to give comprehensive information on all adult deaths due to chronic diseases beyond and including cancer. It will provide new information to help guide program and policy planning.

NELS News 5 features research around ICE Project 5, led by Fred Burge and Bev Lawson, Department of Family Medicine, Dalhousie University.

To be added to our NELS e-mail list and to receive future issues of NELS News, please e-mail nels@dal.ca.

NELS News and Events are posted on our website at nels.dal.ca.

Mortality Follow Back Study: Interview and analysis team

Beverley Lawson, Research Associate in the Department of Family Medicine since 1998, has been integral in developing the program of research on end of life care. This led to obtaining funds for the Experience of care during the end of life: A population-based Mortality Follow Back Study. In addition to being a co-investigator, she is the overall project manager. Bev oversees the sampling of death certificates, the invitations to informants, the extensive interview scheduling and data entry, and she has begun the early data analyses. The Mortality Follow Back Study is a success due to Bev’s dedicated and compassionate work, as well as that of the study interviewers and administrative help.

Cassandra Yonder

Cassandra works as an interviewer for the Study. She has education in Sociology and Gerontology and completed the Certification in Grief and Bereavement offered jointly by the University of Western’s Thanatology department and King’s College. Cassandra is a certified Hypnotherapist, Animal Assisted Therapist and level II Shambhala meditation practitioner. She hopes to develop a centre for grieving families in Nova Scotia.

Cassandra owns a small private practice in bereavement support in Cape Breton, which has expanded to include Death Midwifery. She offers education and services as a Home Funeral Guide.

“I have sincerely enjoyed my job with Dalhousie Family Medicine conducting telephone surveys from my homestead with bereaved people about the End of Life care that their loved ones received during the last month of their life.

Most respondents seem to appreciate the chance to participate in the survey and tend to share wonderfully rich narratives in addition to answering the survey tool questions directly.”

Jillian Demmons

Jillian works as an interviewer for the Study. In her undergraduate work at Mount Saint Vincent University and her graduate study at Yale Divinity School, Jillian explored existential questions of human suffering. To be equipped to better support the existential and spiritual needs of those struggling with serious health issues, Jillian went on to pursue training as a Chaplain focusing on work with senior citizens in Geriatrics and Palliative Care.

“When the opportunity arose to become an interviewer for this study, I was excited; it was the perfect fit for me, as it combined my background in end of life care, geriatrics, and grief support, with my experience and interest in research.

Interviewing people about end of life experiences is very rewarding. Although my role is that of interviewer not Chaplain, in my experience, providing a patient listening ear for those who share their stories is often helpful and healing for the participants. Gathering people’s insights about how to improve end of life care is very interesting as well, and I am excited to see the final results!”

Kristine Van Aarsen

Kristine has been a research associate in the Department of Family Medicine at Dalhousie University since 2009. Her graduate studies in Epidemiology and Biostatistics at the University of Western Ontario developed her interest in research methods.

Kristine provides administrative support and conducts data analysis for the Study. Although the topic of end of life care is a new research area for Kristine, she has found her experience on this project to be very educational and rewarding.

“I feel humbled by the participants in this study who, after going through a loss, are able to share their stories and give us valuable information regarding end of life care.

I would like to thank all participants who have taken the time to complete our interview, you are very much appreciated. I feel very grateful for the opportunity to take part in such a valuable project that has the potential to change care delivery for persons at the end of life.”
Mortality Follow Back Study: Preliminary findings

Six waves of surveys will be conducted. In February 2010, the first wave of interview invitations was sent and by January 2011 waves 1, 2, and 3 were completed. The last survey wave is expected to be in October 2011. In January 2011, 544 of approximately 2,222 eligible informants had contacted the research team and agreed to participate (24.5% response rate). From these informants, 400 surveys have been entered in the database and form the basis of this report. Final reports will be prepared after all survey data is collected and results may change as the number of informants increases.

RESULTS

The informants were usually the next of kin named on the death certificate. Mothers and spouses were most likely to contact the research team and participate in the Mortality Follow Back Study.

Relationship of informant to decedent

Dying in hospital was most common for persons dying of cancer (60.4%), heart disease (53.4%), respiratory disease (64.9%), and digestive conditions (84%). Dying at home was most common for those with blood disorders (50.0%) and cancer (35.6%). The rates of dying in a long-term care facility were greatest for those with an endocrine, nutritional or metabolic disease (58.3%), or mental or behavioural disorder including dementia and Alzheimer's (57.9%).

The location where care was provided for the majority of the last 30 days of life differed from the location of death. Among decedents with the majority of care provided in the home, 47.6% died at home. In contrast, when the majority of care was in hospital, 89.8% died there.

Of those preferring to die in hospital, 85.7% were able to do so, while 11.4% died at home, and 2.9% in long-term care. Similarly, 85% of those wishing to die in long-term care were able to, although the remaining persons (15%) died in hospital.

Of those receiving care at home during their final days in the last week of life, 88.8% experienced a home death; 100% of those in hospital died there. Two percent of persons receiving care at home died in transit to a medical facility. Among those receiving end of life care in a long-term care facility, most (95.7%) died in that location; 4.3% died in hospital.

Of those who voiced a preferred location of death, only 47.7% who preferred to die at home did so; 39.4% who wished to die at home died in hospital, 12.1% in long-term care, and 1 (0.8%) in transit to a medical facility.

Of those who preferred to die in hospital, 85.7% were able to do so, while 11.4% died at home, and 2.9% in long-term care. Similarly, 85% of those wishing to die in long-term care were able to, although the remaining persons (15%) died in hospital.

Among those who changed their mind about where they wished to die (n=24), 18 (75%) initially desired a home death but decided later they would prefer to die in hospital (n=10, 55.6%) or in long-term care (n=7, 38.9%).

Of those decedents spending the majority of their last 30 days at home (results from first two survey waves only) 39% were not told what to expect near death, 54% did not know what to do at time of death, and 27% did not have information about the medications used for symptom management.

When this information was received, specialist physicians and palliative nurses provided it. Informal caregivers provided the majority of care for the decedent's pain (62%), breathing (43%), and anxiety/sadness (62%). Family members provided 81% of the help for the decedent's personal care needs. For these decedents, 50% were female, 61% were married, 53% died of cancer, and 60% had private health insurance above provincial coverage. Their average age was 74 years.
Development of end of life research leading to Mortality Follow Back Study: Past studies using administrative health data linkages

Fred Burge has been Principal Investigator or co-Principal Investigator on 11 projects since 1995 that have led to the Mortality Follow Back Study. Research progressed from looking at two linked databases to linking ten. Knowledge gained from these studies raised questions that will be addressed through the Mortality Follow Back Study which goes beyond the data available from previous retrospective linked administrative data studies.

First end of life data linkage project - From 1995 to 1997 the first data linkage project was completed. Fred, Grace Johnston, and Ina Cummings arranged for the linkage of two databases: the Queen Elizabeth II (QEII) Palliative Care Program in Halifax and the Nova Scotia Centre Oncology Patient Information System, with funding support from the Laboratory Centre for Disease Control, Health Canada. This project explored the utility of using Palliative Care databases in Nova Scotia to provide descriptions of those dying of cancer.


From 1998 to 2000, Fred with others received an Evaluation Research Grant to assess the Rural palliative home care project. Caregivers, providers, and patients were surveyed to evaluate the impact of the new program which aimed to: increase accessibility to palliative care in rural communities; increase support to health care providers and facilitate their increased involvement; develop, implement, and evaluate an overall education curriculum; and define the barriers to receiving palliative care in rural communities.


From two to five databases - With the addition of Beverley Lawson as Research Associate and given her database management skills, the emerging program of research grew from including two databases to five.

In 1999, five administrative databases plus limited Census Canada information were linked. This project, Access to primary medical care for those dying of cancer was funded by QEII Health Services Centre Research Fund. This project was extended to Family Physician palliative care for those dying of cancer: Changes during the 1990s, to include years 1992 to 2000 thanks to funding from the National Health Research and Development Program which became the Canadian Institutes of Health Research (CIHR). This data was utilized for a study to explore physician continuity of care in the project, Family Physician continuity of care for advanced cancer Patients: Does it facilitate (continued on page 5)
(continued from page 4) community-based care? with funding from Cancer Research and Education of the National Cancer Institute of Canada. This set of projects led to many publications.


**Inclusion of data beyond cancer** - From 2002 to 2003, funding from the Health and Stroke Foundation of Canada enabled the study: *End-of-life care and congestive heart failure* which linked three administrative health databases, limited census information, and data captured in the Improving Cardiovascular Outcomes in Nova Scotia (ICONS) database to assess health services and provider continuity of care provided to those diagnosed with congestive heart failure at the end of life.


**Examinations of transitions in place of care** - The Capital Health Research Fund supported further examination of information contained within the QEII Palliative Care Program database linked with limited Census Canada information. The project was called *Health service utilization at the end of life: Transitions in location of care and the associated factors*.


**From five to ten databases** - CIHR funded *Inequalities in end-of-life care for cancer patients: Do they exist and what contributes to them?* from 2005 to 2007 to link ten databases. Seven of these were administrative health databases including the Nova Scotia homecare tracking database (SeaScape). The other databases were Census Canada, family physician density, and long-term care bed density.


From 2006 to 2007, the study, *Emergency department use among palliative care patients*, linking palliative care program data in Halifax with emergency room information was funded by the Capital District Health Authority Research Fund.


**Network and team development** - In 2006, the Network for End of Life Studies (NELS) was formed and funded by a five-year CIHR Interdisciplinary Capacity Enhancement (ICE) grant. NELS ICE is a large team grant involving multiple projects using a variety of methods: [http://nels.dal.ca](http://nels.dal.ca).

**Current** - The Mortality Follow Back Study, informed by projects within NELS ICE, will include linkage to administrative health databases.

In September 2010, Emily Marshall, PhD, an Assistant Professor in the Department of Family Medicine and Melissa Andrew, MD, and Assistant Professor in the Division of Geriatrics at Dalhousie University were approved for NELS ICE New Investigator funding.

Given NELS ICE support, the project, Improved outcomes with a new model of dedicated primary care physician and team approach for long-term care facilities: A mixed-methods study, will include an end of life care focus. Emily is the overall lead for this research; Melissa will be conducting the study Implementation and evaluation of a Comprehensive Geriatric Assessment designed for use in Long-Term Care Settings (LTC-CGA) in relation to end of life care, which is part of the larger project.

In the summer of 2011, there will be a chart review of residents in long-term care. The goal is to identify, particularly for residents who died, the extent of documented end of life care plans; whether death was expected or unexpected; if resident and family wishes for end of life were documented; and if the plans were achieved.

High quality end of life care in long-term care facilities is vital to ensuring desired physical comfort and emotional support, promotion of shared decision-making, respectful treatment of the dying person, information and support for family members of the dying person, and coordinated care across settings.

Capital District Health Authority (CDHA) implemented wide-ranging changes to how primary care is provided in long-term care facilities. The major changes are:

1) A new system of a dedicated family physician for each floor of a facility with participation in weekly care-team plan meetings and on-call coverage;

2) A comprehensive program of interdisciplinary education and training to improve team coordination, communication, and end of life care;

3) Performance measures collected in a regular and systematized way to measure improvements;

4) A extended paramedic team dedicated to providing on-site support in long-term care facilities to avoid hospital transfers;

5) A standardized comprehensive geriatric assessment of health status of each resident.

Outcomes will be examined related to the new models of primary care being implemented. These outcomes include reductions in unwanted and unnecessary transfers to emergency departments, reductions in polypharmacy, and increased team communication.

Emily is responsible for focus groups and interviews with residents, family members, physicians, nurses, paramedics, administration, and staff. The interviews will be conducted to understand the lived experience of the various stakeholders under the new model. This will help determine how end of life care is being addressed by the care team.

Melissa will investigate what the LTC-CGA contributes to end of life care, what gaps remain, and areas for potential improvement.

The LTC-CGA is being implemented as part of the new model of primary care in long-term care facilities where all patients on a single floor will be under the care of a dedicated physician and a clearly coordinated system of on-call coverage. The LTC-CGA will potentially be a powerful tool for assessment and communication in long-term care facilities. However, its uptake and acceptability to end users are not yet known.

The theoretical model that Emily and Melissa will use to operationalize the end of life aspect of their study is a transitional model that illustrates the gradual shift in focus of care towards end of life as frailty and disease severity increases.


Funding for this study is also provided by CDHA; Department of Family Medicine, Dalhousie University; Director of Continuing Care, Nova Scotia Department of Health and Wellness; and Canadian Dementia Knowledge Translation Network.
International Primary Palliative Care Research Group

NELS ICE co-Principal Investigator, Fred Burge, is the Canadian lead for the International Primary Palliative Care Research Group. The research group is comprised of a dozen committed members and 50 plus corresponding members including general practitioners, family practitioners, and researchers from a range of disciplines including social sciences and oncology.

The group first met in Quebec City, in October 2005 as a core of four family medicine researchers: Fred Burge; Geoff Mitchell from Brisbane, Australia; Alan Barnard, from Cape Town, South Africa; and Scott Murray from Edinburgh, Scotland. Scott was also a NELS ICE Visiting Scholar in 2008 when he presented on the UK Gold Standards Framework (http://www.gsfs.scot.nhs.uk/).

The international research group provides collegial support for like-minded researchers who advocate for an improved primary care role in the delivery of palliative care. Primary palliative care researchers are encouraged to present their work and explore international collaboration. It also recognizes the considerable need for palliative care in low-income countries and assists local practitioners develop sustainable and effective services.

Meetings and Presentations

The International Primary Palliative Care Research Group meets regularly, most recently in May 2011 during the 12th Congress of the European Association for Palliative Care (EAPC) in Lisbon, Portugal. At the EAPC conference Scott Murray delivered a plenary presentation to 2,700 delegates from 175 countries on Primary Care and Palliative Care. He emphasized the untapped potential for primary care delivery of palliative care. He specifically noted five key opportunities to more effectively enlist primary care practitioners and teams in the care of persons approaching the end of their lives:

1) All illnesses including all chronic diseases
2) All stages of care and thereby providing earlier and more timely interventions
3) All dimensions of care: physical, psychological, spiritual, and social
4) All settings in the community: home, office/clinic, long-term care, hospice, and
5) All nations so we can and should learn from each other.

Scott noted that in the UK, on average, general practitioners with a roster of 2,000 persons in their practice have 20 deaths per year: 6 die from organ failure, 5 from cancer, 7 from frailty/dementia, and 2 are acute deaths. Therefore, primary care providers need to be prepared to provide palliative care.

The group’s previous meeting was in South Africa, 2009, where Fred presented Building Interdisciplinary Research Capacity in End of Life Care: A Canadian Example which described NELS ICE experiences with building research on end of life care. The group will meet again in October 2012 during the 19th International Congress on Palliative Care in Montreal.

For further information on the primary palliative care researchers and their publications visit: http://www.uq.edu.au/primarypallcare/

Visiting Scholar, Allan Kellehear - Public Health approaches to end of life care

On October 18, 2010, NELS ICE hosted Visiting Scholar Allan Kellehear, PhD. He was the Director of the Centre for Death and Society at the University of Bath, United Kingdom.

Allan presented *Public Health approaches to end of life care* during his visit. The presentation provided an overview of the theory, concepts, and practice that are basic to a public health approach to palliative care. Historically, palliative care has focused its efforts on the bedside management of terminal illness, especially cancer. The health services model employed by palliative care has been an acute care model. Home, hospital, and hospice care have emphasized health service interventions late in the course of an illness, especially symptom management. Psychosocial care has been identified with a professional response from pastoral care, social work, psychology or counseling.

During his presentation, Allan discussed how a complementary population health approach using community development, education, participatory relations, ecological interventions, and health promotion should be incorporated. To date, these have typically been absent from most palliative care programs.

From 1996 to 2006, Allan was Professor of Palliative Care and Director, Palliative Care Unit, School of Public Health, La Trobe University in Melbourne, Australia. He is also the co-editor of *Mortality*, an international journal of interdisciplinary studies in death and dying. In August 2011 he will be moving to Halifax and joining Dalhousie University as a Professor in the School of Health Administration.

Allan will join NELS ICE on September 8, 2011 at the event, Highlighting NELS ICE Successes, to present and enable discussion around potential Next Steps for NELS after ICE.

Theory Examples


Practice Examples


