

Improving end of life care in long term care facilities: Perspectives of healthcare providers

Christine Beck, NELS ICE trainee and Family Medicine resident, has recently completed, *Improving end of life care in long term care facilities: Perspectives of healthcare providers*. Co-authors of this project are Paul McIntyre, Raewyn Bassett and Fred Burge.

Christine was funded as a Transdisciplinary Understanding and Training on Research - Primary Health Care (TUTOR-PHC) scholar during her year with us. TUTOR-PHC is a Canadian Institutes of Health Research (CIHR) strategic training program

End of life care for elderly residents of long term care facilities (LTC) is becoming increasingly complex due to a rising proportion of residents with multi-system chronic diseases, including dementia. Through a literature review Christine found that numerous barriers were regularly described and she found that there is a need to establish effective solutions to overcome

these barriers. Through focus groups enrolling LTC providers within Capital District Health Authority (CDHA), Christine was able to gather perspectives of those directly involved in end of life care in LTC.

Christine's study had three specific objectives: to deepen understanding of the current issues and challenges faced with respect to end of life care for elderly persons living in LTC facilities within CDHA; to elicit proposed solutions from healthcare providers on how to overcome these challenges; and to synthesize the perspectives of participants in order to inform development of a health services intervention for quality improvement.

Christine presented her work in progress on January 15. Her presentation is at <http://nels.dal.ca/ppt/CBeck.html>. Christine has



Christine Beck, MD, with her Fellowship Supervisor and NELS ICE Co-PI, Fred Burge, following Christine's Work in Progress Session on January 15, 2010.

been accepted to present her findings at the 6th Research Congress of the European Association of Palliative Care (EAPC) in Glasgow UK, June 10-12, 2010.

An inductive thematic analysis of the focus group transcripts is being completed. Initial themes that have emerged include familiarity (building strong relationships among residents, family members and staff), access to healthcare resources (within facility and district palliative care services), networking (with other healthcare providers and LTC facilities) and mindset (acceptance of mortality and acknowledging differences between LTC and acute care). A manuscript is being prepared for publication.

Best wishes to Christine as she begins the next stage of her career in Boston.

Welcome to Lynn Lethbridge

In January 2010, NELS welcomed Lynn Lethbridge as the new ICE Analyst.

Lynn has been a researcher at Dalhousie for 15 years. She received her Master's in Economics at Dalhousie, with a focus on physician labour force behaviour and has since been involved in a variety of research topics including health and well-being, poverty and inequality, labour force and gender-related issues. Recent work has included health and human resource planning including simulation modeling. Lynn has authored and coauthored sixteen papers in refereed journals along with numerous government reports and book chapters.



Lynn Lethbridge

Lynn has collaborated previously with NELS ICE investigators, specifically looking at quality indicators at end of life for Eva Grunfeld and Paul McIntyre. These findings are reported in this newsletter (*Quality of End-of-Life Care for the Elderly Dying of Cancer*, page 4).

NELS ICE is pleased to welcome Lynn to the team.

This issue of NELS News features work surrounding ICE Project 6, 'Quality End of Life Care for the Elderly'.

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

Indicators of quality end of life care for the elderly

In 2004, a NELS ICE collaborator, Craig Earle, and his colleagues used indicators of what he called aggressive treatment near the end of life in a study of persons 65 years and older who died of selected cancers in regions of the United States. In 2006, Eva Grunfeld and her team published similar measures in a study of quality indicators from administrative data for breast cancer patients at end of life in Nova Scotia (NS) and Ontario. In 2007, Meaghan O'Brien and others reported differences between nursing home residents and non-residents in end of life care in persons 65 years and older dying of cancer in NS.

This report combines the ideas in the above studies to present indicators of care for the elderly living in nursing homes compared to those not living in nursing homes. The purpose is to begin to investigate whether either group might be receiving overly aggressive treatment near the end of life. Historically palliative care has focused on persons dying of cancer. Therefore, the data reported herein relate to cancer. However, the approach can be adapted to consider end of life care for persons with a range of chronic diseases.

This exploratory study which was carried out in 2008 by Lynn Lethbridge and Alison Zwaagstra used administrative data from various sources. Cancer registry information was linked with Vital Statistics and utilization data including information from the Oncology Patient Information System (OPIS), physician billings and hospital discharge data. Nursing home addresses across the province were matched with place of residence and death on death certificates to establish whether persons were nursing home residents at the time of their death.

There were 10,136 adults who died of cancer in NS from 2000-2003 as indicated by their cause of death. For less than 5%, the death certificate is the initial indication of a cancer diagnosis in the cancer registry and there is no record of treatment for the

disease. Although there are important access-to-care issues for these individuals, the purpose of this study is to examine care for those with a cancer diagnosis that was known prior to death. As such, death certificate only cases are excluded from the analysis. Also excluded were a small number with missing information regarding place of residence and place of death, as well as those under 65 years. There were 7,130 persons who were 65 years of age and older in this study. This includes 893 (12.5%) who lived in a nursing home near the end of life and 6237 (87.5%) who lived outside a nursing home.

Nursing home residents were, on average, six years older than those living outside nursing homes and more likely to be female (58%). Just over 40% of the persons in both groups lived in a rural area (Table 1).

Five indicators of aggressive care near the end of life outlined by Earle et al were measurable (Figure 1). According to OPIS records, chemotherapy was administered to about 15% of individuals in the last two weeks of life for those outside nursing homes while no nursing home residents received it. Non-nursing home residents were more likely to use acute care services. For example, 6.4% of non-residents had more than one emergency department visit in the last month of life compared to 2.8% of the residents. Among the non-residents, 14.4% had more than one hospital admission in the last month of life compared to 5.2% of residents, and 35.6% of non-residents spent at least 14 days in hospital in the last month compared with 13.2% for those in nursing homes. Rates of admission to an intensive care unit in the last month of life were 5.1% for nonresidents and 2.8% for residents.

This analysis has some limitations. The indicators of potentially aggressive care are not controlled for the age difference between residents and non residents. Confidence intervals for the indicator values should be calculated. Reports of the use of chemotherapy in the physician billings should be considered since some chemotherapy may be provided outside of the cancer centre. Also, there was no information available on the length of time that the residents had lived in a nursing home. Some persons could have moved from their own home or hospital to a nursing home close to the time of their death. More current years of data should be analyzed. Access to hospice and palliative care should be incorporated.

Another study by Eva Grunfeld and her team reported in 2008 that patients, their families and health care providers question the use of chemotherapy near the time of death and the use of hospital services as indicators of poor quality end of life care. They emphasized the need for choice of care *(continued on page 3)*

Table 1:
Characteristics of persons 65 years and over who died of cancer in Nova Scotia from 2000-2003.

| | Nursing Home Residents | Non-Nursing Home Residents |
|----------------------|------------------------|----------------------------|
| Mean age (range) | 83.3 (65-103) | 77.3 (65-102) |
| Sex (%) | | |
| Male | 42% | 56% |
| Female | 58% | 44% |
| Rural residence (%) | 44% | 41% |
| Died in hospital (%) | 20% | 59% |

Indicators of quality end of life care for the elderly

(continued from page 2) and the need to consider community and family resources in decisions on the best place of care. Until very recently, there have been no community hospice facilities in the province.

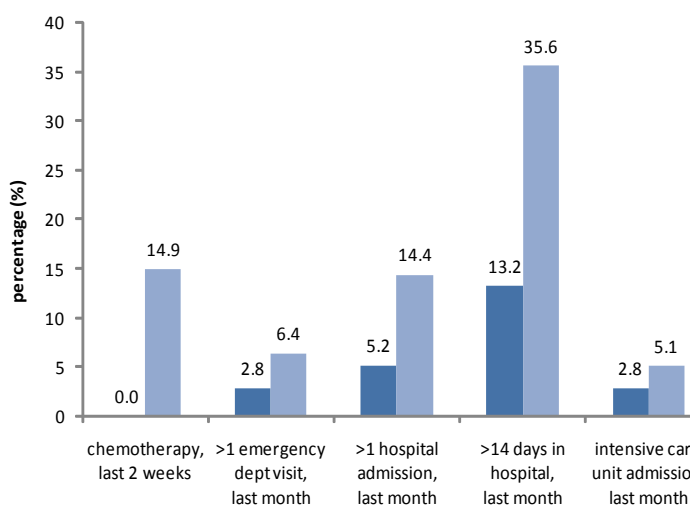
Hospital-based palliative care programs have been available since 1988 in Halifax and Sydney. All districts of the province now have a palliative care program. Benchmarks for quality end of life care across the province need development. Disease-specific and across-disease indicators of quality care should be incorporated for all chronic diseases with a terminal stage. This includes cancer as well as chronic obstructive pulmonary disease, congestive heart failure, advanced renal and many other diseases.

While comparable to the rest of Canada, rates of dying in hospital in NS have been high compared to other countries. Studies by Fred Burge and others have shown that even though these rates of dying in hospital have been slowly decreasing, and use of palliative care increasing, a disparity in access remains for the elderly.

Another point to consider is that nursing home residents are more likely than non-residents to have Alzheimer's disease. Judith Fisher (see page 4) is beginning to help us understand the end of life situation for persons with Alzheimer's.

Research has suggested those in nursing homes may be vulnerable to under-treatment by some measures such as pain management (page 5 reports investigations and interventions by Elsie Rolls and her team). Judith and André Maddison have also reviewed literature

Figure 1:
Indicators of potentially aggressive care at end of life.



on the advisability of discontinuing long term chronic disease preventive medications, such as statins to lower cholesterol levels (this work will be featured in a future NELS News issue).

While there may be a lack of consensus on what is aggressive treatment at the end of life, this report raises questions that require further attention. Persons living outside of nursing homes may have a higher probability of receiving overly aggressive treatment near the end of life. Over treatment in terms of acute care utilization and aggressive disease-specific treatments in the last months of life may be indicators of less than optimal quality of care. To what extent does quality care for terminally ill persons include palliative care? Beyond quality indicators developed from administrative data, there are other means of investigating the quality of care (e.g. Christine Beck's work on page 1). In new work, Fred Burge and Beverley Lawson are carrying out a mortality follow-back survey that uses interviews with the next of kin after the loss of a loved one to assess satisfaction with care. NELS studies are designed to increase our understanding of the provision of quality care at end of life for all persons.

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Alzheimer's Disease at end of life

NELS ICE Post Doctoral Fellow, Judith Fisher, has looked at end of life and Alzheimer's disease. Alzheimer's is the most common form of dementia and the symptom burden (confusion, disorganized thinking, impaired judgment, disorientation to time and space and a difficulty communicating) present challenges for end of life care. Judith describes persons dying when Alzheimer's was either the underlying or other contributing cause of death and examined factors associated with dying in-hospital when Alzheimer's is an underlying or contributing cause of death.

The study population for the project was all Nova Scotians age 65 years or more who died from 1998 to 2005 (N = 63,431) according to the Nova Scotia Vital Statistics maintained by the Population Health Research Unit at Dalhousie University. Alzheimer's was defined as ICD-9 331.0 (1998-1999) and ICD-10 G30 (2000-2005). Descriptive analyses were conducted to characterize the population by age, sex, cause of death and location of death (in-hospital vs. out of hospital); differences by

population characteristics were examined using chi square tests. Binary logistic regression models examined factors associated with dying in-hospital, adjusting for age, sex, number of causes of death, 'cause of death' (Alzheimer's as underlying vs. contributing cause) and the interaction between sex and 'cause of death'.

The incidence and prevalence of all dementia-related disorders, including Alzheimer's disease increase with age. Approximately 1 in 11 Canadians age 65 and older has some type of dementia. The increased risk of dementia with advancing age is particularly evident after age 75 and among the 'oldest-old', i.e. age 85 and older. Figures 2 and 3 illustrate these trends with Nova Scotia data, and demonstrate the increasing number and impact of dementia-disorders with advancing age.

A paper of the completed analyses is being prepared for publication submission and further analyses examining the patterns of contributing causes evident in this population and the implications for end of life care is being considered.

Figure 2:
Total number of deaths from all causes in Nova Scotia (1998 to 2005) by age group identifying Alzheimer's disease and other dementia.

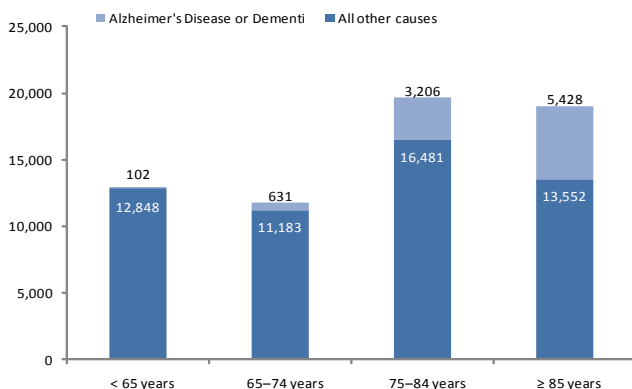
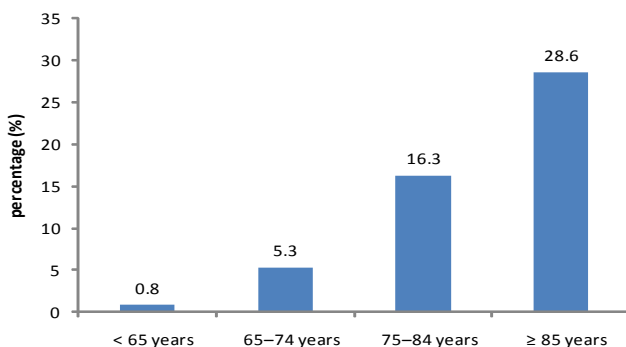


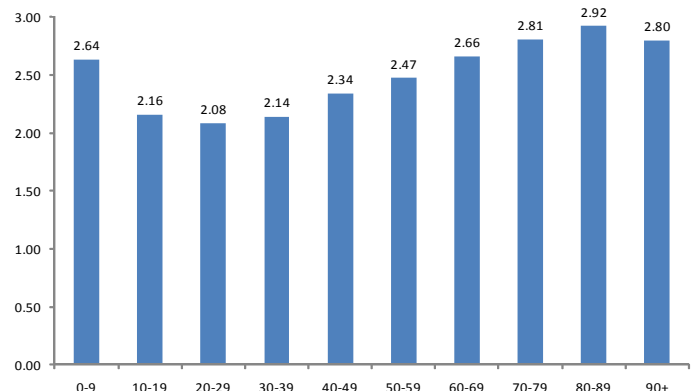
Figure 3:
Percentage of total deaths in Nova Scotia (1998 to 2005) in which Alzheimer's disease or other dementias are included on the death certificate, by age group.



Co-morbidities by age

Up to 13 causes of death can be recorded on the Nova Scotia death certificate. Among adults who died from 1998 to 2005, the number of recorded causes of death increased with advancing age reflecting greater co-morbidity (Figure 4). The average number of co-morbidities increased from 2.08 for those aged 20-29 years to a high of 2.92 for ages 80-89. There was a slight decline to 2.81 for those aged 90 years and over. Children also had relatively high levels of co-morbidity with a rate of 2.64 for those aged 0-9 years. It is important to consider the implications of co-morbidities while planning care for those at end of life.

Figure 4:
Average number of causes of death recorded on the death certificate per decedent by age group for all deaths in Nova Scotia, 1998 to 2005



Pain management and philosophy of care in Veteran's care

Elsie Rolls, the Director of Veterans Services at Camp Hill Veteran's Memorial Building in Halifax has been a Canadian Health Services Research Foundation (CHSRF) Executive Training for Research Application (EXTRA) Fellow over the past two years. Elsie has been working with an interdisciplinary team to improve pain assessment and management and develop a philosophy of care that incorporates palliative and end of life care at Veterans' Services. Her EXTRA mentors have been Barb Hall, Vice President, Person Centered Care at Capital Health and Grace Johnston, NELS ICE Principal Investigator. Elsie has consulted with Paul McIntyre and others on the NELS ICE team.

Elsie's EXTRA Project, *Pain Management and Philosophy of Care in Veterans' Long Term Care*, focuses on the development and implementation of a care and service delivery philosophy as well as the development of a formalized pain assessment and management program at Camp Hill.

Camp Hill is a Long Term Care facility for Veterans of WWII and the Korean War. Home to 175 veterans, Camp Hill has a comprehensive long term care service. The EXTRA project resulted in part from lower than acceptable satisfaction scores on pain management at Camp Hill on the annual audit by Veterans Affairs Canada (VAC). With the average length of stay shifting from 22 months in 2005 to 5 months in 2008, the facility also needed to develop a philosophy of care that more clearly incorporates palliative care and address issues surrounding their pain assessment and management.

In March 2009, Elsie carried out an audit of pain management for 49 veteran residents. Slides of her 2009 presentation to NELS ICE are at <http://nels.dal.ca/ppt/ERolls2009.html>.

This audit revealed that, from the electronic minimum data set records that contain data on admission and quarterly thereafter, there was a report of daily pain for only 14% of the veterans, and that the pain intensity was mild for 62%. However, a review of their charts showed that 98% of the Veterans had a diagnosis that could cause pain. In fact, on average, each resident had 2.6 diagnoses that could cause pain including arthritis, wound or skin break down, congestive heart failure, chronic obstructive pulmonary disease, osteoporosis, paralysis, diabetes, gum disease and joint replacement (Table 2).

At this initial audit in March 2009, 53% of residents had a regular order for an analgesic and

75% had a PRN (as needed) order. Among the regular orders, 93% were for regular acetaminophen of 1-3 tablets daily or up to four times a day. The as-needed orders were 89% acetaminophen with the other orders being Tylenol 2 and 3 (Table 3). The literature about pain management in the elderly points out that older adults receive less than adequate pain treatment and that the most commonly prescribed analgesics were aspirin and acetaminophen plain.

In 2009, much education was carried out that included sharing the audit data. Standardized pain assessment tools were implemented for residents who can and cannot self-report pain. The Abbey scale was chosen by the staff for Veterans who are not able to self report because it is completed while regular care is being done and the Veteran being moved, such as during bathing, walking or during turning. The Abbey pain scale is an observational tool that measures six behavioural symptoms that can suggest the presence of pain. Pain as the fifth vital sign was also added to the daily care flow sheets, therefore requiring that each resident be assessed at least three times a day, once during each 8 hour shift. A protocol was developed and related education provided to the Camp Hill staff. Education on pain assessment and management has reached over 80% of the staff. In addition to pain medications, there has been a focus on improving non-pharmacological treatments for pain including acupuncture, massage therapy, music therapy, hot packs, physiotherapy and the use of pressure reduction bed surfaces for each of the Veterans' living areas. *(continued on page 6)*



Elsie Rolls, Director of Veterans Services at Camp Hill Veteran's Memorial Building, Halifax, Nova Scotia.

Table 2:
Pain Assessment at Initial Audit, March 2009.

| Pain Frequency | | | Pain Intensity | | |
|----------------|-----------------|------------|----------------|---------------|----------------------------|
| No pain | Less than daily | Daily pain | Mild pain | Moderate pain | Horrible excruciating pain |
| 57% | 29% | 14% | 62% | 28.5% | 9.5% |

Table 3:
Pain Management at Initial Audit, March 2009.

| Residents with regular order for analgesic | Residents with PRN analgesic orders | Residents that received PRN analgesic in previous week |
|--|-------------------------------------|--|
| 53% | 75.5% | 8% |

Pain management and philosophy of care in Veteran's care

(continued from page 5) Concurrently, the philosophy of care has been strengthened to incorporate palliative and end of care and therefore more accurately reflect the full scope of care and service that is needed based on the population of Veterans now being served.

In December 2009, nine months after the first audit, a follow-up audit of another 49 veterans was completed. Because of the average short length of stay of residents at Camp Hill, most of the participants in the December audit were not the same as the 49 veterans in the March audit. The findings show considerable progress was made between March and December 2009 in terms of increased diversity in the types of orders for pain medication – less use of acetaminophen plain and greater use of stronger analgesics such as hydromorphone and acetaminophen with codeine (Figure 5). The December audit also showed that the number of residents that had orders for more than one as needed analgesic order had increased, i.e. order for acetaminophen plain plus an order for a stronger analgesic in case the acetaminophen was not effective. Non-pharmacological pain management increased from 12% to 49% (Figure 6).

The Philosophy of Care was drafted with input from staff, experts and VAC. It is now receiving input from the veterans, their families and the remaining staff. Ongoing work includes the addition to the protocol of spiritual and psychosocial pain assessment and management, development of an interdisciplinary staff orientation program that includes education on the philosophy and dealing with all aspects of pain as interdisciplinary team members.

Figure 5:
Analgesics Pain Management:
Comparison between March & December 2009

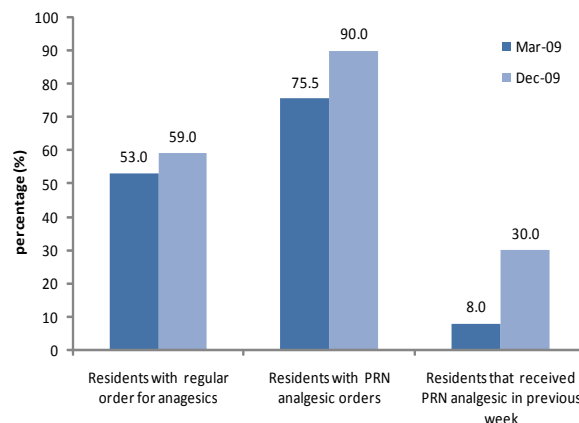
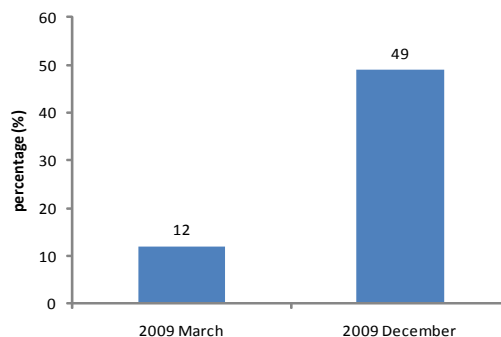


Figure 6:
Non- Pharmacological Pain Management:
Comparison between March & December 2009



Dr. Kevin Brazil presented Supporting Quality Care for the Dying in Long Term Care in Halifax, NS.

Visiting Scholar - Kevin Brazil

Kevin Brazil visited Halifax, Nova Scotia as a NELS ICE Visiting Scholar from January 13 -15, 2010. Kevin is the Director of the St. Joseph's Health System Research Network based in Hamilton, Ontario.

He holds a faculty appointment as Professor in the Department of Clinical Epidemiology and Biostatistics and Division of Palliative Care in the Department of Family Medicine at McMaster University where he is the Site Director for the Ontario Training Centre for Health Services and Policy Research. His research interests include health services research, community and long-term care, health care for the older adult, and end of

life care. He is a co-investigator with the other CIHR vulnerable populations ICE grant that focuses on palliative care.

Kevin presented his perspective on the state of LTC in Canada in his presentation, Supporting Quality Care for the Dying in Long Term Care. Slides and audio from this presentation is at <http://nels.dal.ca/visiting scholars.html>.

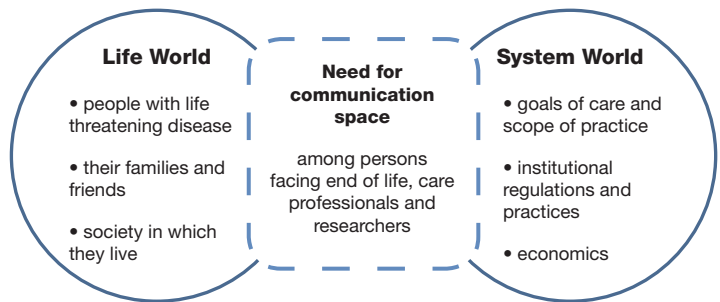
Kevin met with many NELS ICE investigators and collaborators to discuss mutual interests including his work in applying Habermasian critical theory to critique doctor-patient communication as it applies to end of life care (see page 7).

Habermasian critical theory as it applies to end of life care in long term care

Our values, beliefs and past experiences affect how we interpret what others say. The words we use can have very different meanings for people meeting together to discuss options for palliative care. Applying the theory of the philosopher, Jürgen Habermas, the lived experience or Life World encounters the System World of the delivery of care at end of life. The System World is dominated by the ‘rational’ and oriented towards ‘success’ as defined by the ‘system world’. It operates with a privileged discourse used by institutions and professionals. In contrast, the patient and family live within the Life World which is a world of negotiation, emotions, moral positions, and maintenance of dignity and control. The system and life worlds may ‘collide’ because their goals, principles and discourse differ. Communication methods and the meaning of the words may also differ. Effective communication requires creating space for mutual understanding and meaningful

dialogue. This communication space between the lived world and system world is represented in Figure 7.

Figure 7:
Framework from meeting with Kevin Brazil to discuss adapting Habermasian ideas to gain insight into end of life communication.



NEWS & EVENTS

NELS ICE / BHCRI Call for Basic Science Projects

NELS ICE, in collaboration with the Beatrice Hunter Cancer Research Institute (BHCRI), are accepting Letters of Intent for a new award opportunity based in fundamental (basic science) research that focuses on improving prognosis or symptom control for persons at end of life with cancer and other chronic diseases. This new initiative is an attempt to further expand our interdisciplinary research team to improve care at end of life.

Please visit <http://nels.dal.ca> for more on this award. Letter Submissions are due April 14.

UPCOMING ISSUES

Future issues of NELS News will continue to feature ICE Project Streams. Past issues of are available at <http://nels.dal.ca/nelsnews.html>.

NELS News questions and comments can be directed to the ICE Coordinator at nels@dal.ca.

18th International Congress on Palliative Care | October 5-9

NELS ICE will host a special reception during the 2010 International Congress on Palliative Care in Montreal, on Thursday, October 7 from 12:30pm - 1:45pm. The NELS Reception will showcase ICE work at the Congress and provide an opportunity to acknowledge ICE successes and NELS on the national and international scene. More information on the NELS Reception will be available at <http://nels.dal.ca>.

More information on the Congress is at <http://www.pal2010.com>

ACKNOWLEDGEMENT

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PRESENTATIONS

Upcoming Work in Progress Sessions

12:30pm - 1:30pm | Rm 544
Bethune Building, 1276 South Park Street
RSVP: nels@dal.ca

Wednesday, March 31

Heather Castleden, PhD
Photovoice modified to maintain cultural continuity

Friday, April 16

Judith Fisher, PhD
Alzheimer’s disease at end of life

Friday, May 7

Paige Moorhouse, MD
Delivering palliative and end of life care

Thursday, May 20 (Location TBD)

Graeme Rocker, MD
INSPIRED program for community based COPD Care

Wednesday, June 23

Grace Johnston, PhD
Proposed Gold HELP registry to support end of life care