

Literature Review of “Integrated Care”
for
The Irish Hospice Foundation’s
Hospice Friendly Hospitals Programme

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Introduction

The Irish Hospice Foundation (IHF) *Hospice Friendly Hospitals Programme* (HFH) is being developed to promote the integration of mainstream hospice principles into hospital practice. This innovative approach is aimed at improving the lived experience of dying patients and their families as they navigate through hospital systems. Because hospitals are currently oriented towards cure and aggressive treatment interventions, the programme is advancing a shift in hospital orientation that would address the needs of dying patients and their families. The changes proposed by the programme are intended to improve conditions specifically from the perspective of such patients and families.

The Hospice Friendly Hospitals Programme is oriented around the four key themes of Integrated Care, Communication, Dignity & Design, and Patient Autonomy. Per the request of the IHF, the following is a systematic literature review for the theme of Integrated Care. Due to the brief time-frame for this endeavour, the systematic review should be viewed as a scoping exercise that provides a structured overview of the literature.

Aims and Scope of the Review

The aim of this systematic literature review is to identify and summarize the academic and “grey” literature on the topic of integrated care. For the purposes of this project, the concept of integrated care refers to the incorporation of attitudes, programs, clinical interventions, and organizational systems oriented towards dying patients and their families into the services and administration of acute and community hospitals.

Integration suggests that such incorporation is widespread and interwoven rather than haphazard and isolated. This type of integration may occur at various levels within the hospital, including clinical practice, service design, program design, and institutional organization and administration. Based on the HFH Programme description, the review aims to cover the patient and family experience from the time of admission to the hospital, through the duration of the hospital stay, and into the post-death period which includes autopsy procedures and bereavement services. Integration that bridges the hospital to community resources, such as hospices and other agencies, is not addressed in this report because of the specific focus on the hospital environment.

Methods

Initial exploration of the term “integrated care” revealed its limited utility for this review. The term is used in a variety of applications in the literature on palliative and end of life care, but these applications do not include the use of the term sought in the HFH Programme. More commonly, the term is used to discuss incorporation of a palliative care consultation team into the existing medical structure of hospitals, or the integration of palliative care into oncology and other specialty practices within the hospital. The idea of making hospitals as a whole more comfortable and responsive for patients and families facing dying and death is one that the literature does not address directly. Consequently, we have had to construct an alternate approach to the literature review. Given the hospital-wide perspective of integrated care necessary for this review, we have explored the literature that addresses components of integrated care. By describing the elements that comprise hospital-wide integration, we hope to delineate the boundaries of

the literature that contributes to understanding hospital-wide incorporation of services and organization for dying patients and their families.

Grey Literature

We identified grey literature in a number of ways. Appendix 3 contains the list of grey literature included in the review. We explored the website of the National Library for Health (NLH) which contains references and links to a variety of health-related resources. Although numerous documents related to palliative care appear on the NLH website, many are disease specific, procedure specific, population specific, or community-oriented. Although no documents were available directly on integrated care in hospitals, we chose a limited number of documents that broadly relate to the literature review and include small sections of relevant information.

To further identify grey literature, we used electronic listserv media to contact colleagues in the field of palliative and end of life care, requesting their recommendations for documents or programs that might be relevant to the review. We also explored websites of palliative care organizations, including but not limited to the Center to Advance Palliative Care, American Academy of Hospice and Palliative Medicine, Association of Oncology Social Work, American Psychosocial Oncology Society, British Psycho-oncology Society, International Psycho-oncology Society, and National Hospice and Palliative Care Organization.

Academic Literature

We identified 5 electronic databases for the academic literature review. These include the British Nursing Index (BNI), Cumulative Index to Nursing & Allied Health Literature (CINAHL), Evidence Based Medicine (EBM) Reviews which includes the Cochrane Database of Systematic Reviews, Excerpta Medica Database (EMBASE: a European oriented medical database), and PubMed [a service of the United States National Library of Medicine (NLM) and National Institutes of Health (NIH); it includes MEDLINE]. We searched each database with a number of terms and term combinations (see Appendix 1). Terms were chosen to access information focused on the hospital setting, describing integration of care in the form of continuity of care and care pathways, and in the context of palliative and end of life care, including death and bereavement. Electronic searches were limited to the years 1990 to 2006.

Appendix 2 presents the number of articles found in the initial search of each database using the terms specified in Appendix 1. The titles of the articles identified in the initial search were screened for inclusion in the review. Criteria for inclusion of articles were the following:

- Pertains to palliative and/or end of life care
- Pertains to the hospital setting
- Pertains to an approach, service, program or organizational element that may
inform integrating care in the hospital setting
- Not specific to one clinical diagnosis or procedure

Since the search focus was not directly on integrated care but rather on identifying elements that contribute to integrated care, titles were also screened for “face value” of whether the article might inform the topic of integrated care. Because it was not always

possible to determine from the title to what degree the above criteria were met, articles were kept in the review list if they appeared to have potential for inclusion.

The identified titles from each database were then re-searched to provide an article list that included abstract summaries for the identified titles. Abstract summaries were then screened for the original search criteria. The articles chosen from the abstract summaries were then cross-referenced to eliminate duplication across the databases. The final list of articles was thus identified for inclusion in the review.

We realized early in our review process that there appeared to be clusters of topics that were appearing in our database searches. Using the final list of articles, we separated the articles into clusters that formed in the literature. Cluster titles include the following:

- Integrated care pathways
- Elements of palliative care
 - Principles for care
 - Pain and symptom identification and management
 - Family
 - Communication
 - Individual staff and team behavior
 - Additional elements
- Pediatric palliative care
- Intensive care
- End of life care decisions
 - Withholding and withdrawing life sustaining treatment
 - Do not resuscitate (DNR) orders
 - Advance care planning
 - Ethics committees and policies
- Autopsy and organ donation
- Bereavement

We chose a primary article from each cluster to examine thoroughly for the review and used the remaining articles in the cluster to enhance discussion of the cluster topic in relation to integrated care. Several articles from the cluster *Integrated care pathways*

were examined more thoroughly for the review due to their potential for directly informing the topic of integrated care.

Results

The literature in palliative care repeatedly emphasizes the need for improving care of dying patients and families. Palliative care for patients dying in the hospital should promote the basic tenets of palliative care that include identification of a patients' care preferences and goals of care, coordinated interdisciplinary care, identification and management of symptoms and suffering, attention to psychosocial and spiritual issues, communication between care providers and patients and/or family members, and promotion of dignity. The hospital environment has seen increased trends towards the presence of palliative care services. In many hospitals, such services take the form of a special palliative care team, service, or ward that focuses on the needs of dying patients and their families (Fischberg & Meier, 2004; Higginson, Finlay, Goodwin, Cook, Hood, Edwards, Douglas, & Norman, 2002).

The literature review related to integrated care has revealed several clusters of literature that address elements of integrated care. These clusters are summarized below, starting with a systems focus and progressing through the clusters as they pertain to the patient/family journey through care. The first cluster, which focuses on integrated care pathways, does not address hospital-wide integration but offers several models of partial integration that could inform a programme of broader integration. The second cluster touches on many elements of palliative care that would need to be considered in designing an integrated hospital experience. The clusters that follow focus on two

specific population settings: the intensive care unit and pediatric care. Each of these involves unique circumstances, along with universal palliative care lessons, that would need to be integrated into a hospital-wide approach. Several clusters related to end of life care decision making are presented, followed by clusters focused on processes following death, including autopsy and bereavement.

Integrated care pathways

The literature offers several examples of integrated care pathways designed to improve care of dying patients and their families in the hospital setting. The pathways provide a structure for both educating health care providers and performing clinical services. They include such information as how to identify a patient appropriate for inclusion on the pathway and how to identify and manage symptoms associated with end of life. Many of the pathways are modifications of a small number of well-known pathways. Several examples are mentioned below, followed by a summary of elements noted as important to the success of the pathways.

The key pathway for numerous models in the United Kingdom is the Liverpool Care Pathway (LCP) developed by the Royal Liverpool University Trust and the Marie Curie Centre Liverpool (see website <http://lcp.mariecurie.org.uk/>). The pathway is designed to address hospital care of patients in the last 2 days of life and has been applied at hundreds of hospitals. It applies the principles of hospice care to non-hospice settings. The LCP promotes communication among the health care professionals, communication with the patient and/or family, comfort measures, appropriate and timely use of

medications, discontinuation of inappropriate interventions, psychological and spiritual care, and care of the family, including bereavement care.

Numerous hospitals either use the LCP or create a modified version. A few of the modified versions published in the literature are discussed to illustrate the variations that have been implemented. For example, an expanded version of the LCP has been developed in Manchester, UK. It is not limited to the last 2 days of life although it does tend to focus on the last several days of life. The pathway has been implemented for the past 2 years not only on the oncology ward but on most hospital wards, excluding Accident & Emergency and a few other specialty wards. The only publication about this pathway focuses on the role of the clinical facilitator in implementation of the pathway (Mellor, Foley, Connolly, Mercer & Spanswick, 2004).

In South Wales, a palliative care team implemented a modified version of the LCP pathway in a district general hospital and six community hospitals (Mirando, Davies, & Lipp, 2005). The pathway was used for patients with malignant and non-malignant diagnoses, with a large number of patients with non-malignant diagnoses cared for via the pathway. Noteworthy in the implementation of this pathway is that training sessions included non-clinical staff such as housekeeping staff, porters, and administrative and clerical staff. A medical record audit suggests the pathway improved care of the dying in the hospital.

In Birmingham, UK, a Supportive Care Pathway was developed to care for dying patients and families (Main, Whittle, Treml, Woolley, & Main, 2006). The goal was to go beyond the LCP focus on the last few days of life and address needs of patients in the broader framework of the last year of life. The name Supportive Care Pathway was

chosen due to staff reactions to “palliative care” terminology that at times limited application of the pathway to patients who were diagnosed with cancer or seen as actively dying. The program was piloted towards older people in the hospital but was not restricted to specific diagnoses. There has been no formal research assessment of the pilot program but anecdotal feedback from staff has been positive.

In the United States, the Palliative Care for Advanced Disease (PCAD) pathway was developed by the Department of Pain Medicine and Palliative Care at Beth Israel Medical Center in New York (Bookbinder, Blank, Arney, Wollner, Lesage, McHugh, Indelicato, Harding, Barenboim, Mirozyev, & Portenoy, 2005). The pathway details are on the website (http://www.stoppain.org/for_professionals/content/PCAD/pcad.asp). PCAD consists of a carepath, a daily flowhseet, and a physician order sheet with standard orders for symptom control. Evaluation of the PCAD intervention showed that units where it was implemented were more likely to have Do Not Resuscitate (DNR) orders, and a greater number of symptoms assessed increased significantly on all units, even those not implementing the PCAD intervention.

A modified version of the PCAD pathway used in a Veterans Affairs Medical Center in the United States added symptom management guidelines, a computerized discipline-specific assessment template and integration of a computer alert to members of the clinical team when a patient is placed on the pathway (Luhrs, Meghani, Home, Drayton, O’Toole, Paccione, Daratsos, Wollner, & Bookbinder, 2005). Furthermore, there are weekly interdisciplinary meetings. Questions such as “Is this patient likely to die during this admission?” or “Is this patient a candidate for comfort care?” are used to identify patients for the pathway, and any member of the team can identify the patient.

Evaluation of the program showed that patients on the PCAD pathway were more likely to have documentation of care goals and plans of comfort care, fewer interventions, more symptoms assessed, and more symptoms managed according to the PCAD guidelines.

Discussions in the literature on integrated care pathways suggest that several elements contribute to the success of a pathway. Each of these pathways involves educational components that train the hospital staff, usually clinical staff, in the implementation of the pathway. Such educational training of the clinical team is central to the use of the pathway in the hospital setting. The importance of having a project manager/coordinator who serves as a local champion for the pathway is mentioned repeatedly. This person's regular interaction with staff is central to their role in providing the training for the pathway and promoting its use on the wards. Finally, the commitment of senior nursing and medical personnel to the use of the pathway is critical to its application. This support from clinical leadership and management is viewed as an important aspect of pathway success.

Elements of palliative care

A thorough overview of the literature on quality palliative and end of life care is outside the scope of this review. However, a subset of the literature in our review provides insights into components of palliative and end of life care, including those valued by patients, family members and health care providers. Many of the reports in the literature are based on hospital services provided in the context of palliative care consultation teams or other forms of palliative care specialty services. Nonetheless, the palliative care components described may be considered suggestions or underlying

principles for clinical practices and services to be integrated into the wider hospital environment.

Studies on dying in the hospital setting use a variety of methods to research the experience of dying. Qualitative methods used in the literature include focus groups, interviews, non-participant observation, and chart reviews. Examination of hospital trends is often conducted using quantitative methods that explore hospital data bases, surveys, and numeric approaches to chart review. Since the focus of the HFH is on the experience of patients and families, this section will discuss components of palliative care that are directly relevant to that experience.

The literature includes numerous articles about principles of palliative care as well as specific applications of these principles. Overall, palliative and end of life care is intended to relieve suffering through measures that improve comfort and address psychological, social and spiritual needs of the dying patient and family (Counsell, Adorno, & Guin, 2003). One article discussing palliative care in hospitals summarized palliative care activities as providing assessment and treatment of pain and other symptom distress, communicating with patient, families and colleagues, supporting complex medical decision making and goal setting based on identifying and respecting patients' wishes and goals, and promoting care coordination, continuity and support for patients, families, and professional colleagues (Meier, 2006). Most of the literature discusses palliative care as interdisciplinary, requiring a team and teamwork. Noted but not central in the literature reviewed are the roles of specific disciplines and the importance of team dynamics and interdisciplinary coordination. An Australian study highlighted palliative care practices needing improvement: spiritual support, cultural

needs, grief and bereavement support, pleasant surroundings, and adequate privacy and facilities for families (Llamas, Llamas, Pickhaver, & Piller, 2001). Another article highlighted the importance of integrating palliative care services into care for people with intellectual disabilities (Botsford, 2000). Although not the focus of any single article in the review, consideration of the hospital's cultural setting, as well as the cultural needs of the patients, family and staff, is considered an underlying aspect of high quality palliative care. Several elements of palliative care are discussed in the literature reviewed. Before highlighting these elements, we briefly mention a seminal study in palliative care.

One study that requires specific mention is the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) which is represented extensively in the palliative care literature. This research was conducted in five US teaching hospitals in the early 1990s and involved a 2-year prospective observational study followed by a 2-year controlled clinical trial with 4804 patients and physicians. This large scale study provided extensive information on the experiences of patients with one or more of nine life-threatening diagnoses, and the results of the observational phase of the study highlighted substantial shortcoming in the care of seriously ill hospitalized adults (Lynn, Teno, Phillips, Wu, Desbiens, Harrold, Claessens, Wenger, Kreling, & Connors, 1997). Major issues for patients were the following: understanding their situation, communication and decision-making, advance planning, do not resuscitate orders, and general support, including support for loss and grieving (Murphy, Kreling, Kathryn, Stevens, Lynn, & Dulac, 2000). Family members reported notable dissatisfaction with patient comfort and with communication and decision making (Baker, Wu, Teno, Kreling, Damiano, Rubin, Roach, Wenger, Phillips, Desbiens,

Connors, Knaus, & Lynn, 2000). The intervention phase of SUPPORT involved a nurse-based intervention that provided survival estimates to physicians and facilitated communication among patients, families and staff. The intervention failed to improve care or patient outcomes, including patient-physician communication (SUPPORT Principal Investigators, 1995). Nonetheless, SUPPORT was a critical study in palliative care research, highlighting several elements of palliative care that are discussed below.

Pain and symptom identification and management

A clear cluster of palliative care interventions in need of improvement is that of symptom identification and symptom management (Heyland, Groll, Rocker, Dodek, Gafni, Tranmer, Pichora, Lazar, Kutsogiannis, Shortt, & Lam, 2005; Irvine, 1993; Toscani, Di Giulio, Brunelli, Miccinesi, & Laquintana, 2005;). Family members noted the importance of patients' comfort in multiple studies (Baker, Wuk, Teno, Kreling, Damiono, Rubin, Roach, Wenger, Phillips, Desbiens, Connors, Knaus, & Lynn, 2000; Teno, Casey, Welch, & Edgman-Levitan, 2001). Symptoms commonly needing attention in palliative care include difficulty breathing (dyspnea), respiratory secretions, restlessness, agitation, affective distress (including depression and anxiety), fever, nausea, vomiting, delirium and pain (Cantor, Blustein, Carlson, & Gould, 2003; Goodlin, Winzelberg, Teno, Whedon, & Lynn, 1998; Pantilat, 2002; Seah, Low, & Chan, 2005). Pain receives specific attention in the literature, cited as a persistently un- or under-treated element of end of life and a key reason for referral to specialist palliative care (Bostrom, Sandh, Lundberg, & Fridlund, 2004; de Wit, van Dam, Vielvoye-Kerkmeier, Mattern, & Abu-Saad, 1999; Menzies, Murray, & Wilcock, 2000; Meunier-Cartal, Souberbielle, & Boureau, 1995). A study of bereaved family members reported that 54%

indicated their loved one experienced moderate to severe pain in the last week of life (Tolle, tilden, Hickman, & Rosenfeld, 2000).

Family

The importance of family participation clearly emerges in the literature (Irvine, 1993). Family members noted the importance of helping families to understand what to expect as their loved one approaches the end of life (Hodges, London & Lundstedt, 2006). Research that included both observation and interview data determined that patients' families were key participants in the dying process (Pincombe, Brown, & McCutcheon, 2003). Families' attitudes, presence, or absence all had significant impact on the manner of the patient's death, the comfort of the patient, and the behavior of the health care staff. In another study, patients who had a family member present at death were more likely to have DNR orders, to have treatments withdrawn, and to receive narcotics before death (Tschann, Kaufman, & Micco, 2003). Thus, reduced technological interventions and increased use of comfort care were exercised. Presence also arose in a study of bereaved family members; family members of people who died in hospital rather than hospice more commonly noted regret at not being present at the death of the loved (Seale & Kelly, 1997). Although an in-depth view of the role and care of family is beyond the scope of this review, it is clear that inclusion of and care for family is an integral component of palliative care.

Communication

The need for better communication in the care of dying patients and families arose in much of the literature (Baker, Wuk, Teno, Kreling, Damiono, Rubin, Roach, Wenger, Phillips, Desbiens, Connors, Knaus, & Lynn, 2000; Edmonds & Rogers, 2003;

Heyland, Groll, Rucker, Dodek, Gafni, Tranmer, Pichora, Lazar, Kutsogiannis, Shortt, & Lam, 2005; Hodges, London & Lundstedt, 2006; Irvine, 1993; Pincombe, Brown, & McCutcheon, 2003). This communication is divided into (a) communication between the professional care providers and the patient and family, and (b) among the health care providers. The need for improved physician communication (Hodges, London, & Lundstedt, 2006; Schreiner, Hara, Terakado, & Ikegami, 2004) as well improved nursing practices that do not ‘block’ communication (Costello, 2006) are noted.

Recommendations by one study regarding how to improve care of the dying included several communication related items: discussing prognosis and goals of care, pursuing documentation of advance directives, discussing foregoing specific treatment and/or diagnostic interventions, and engaging in discharge planning (as relevant) (Manfredi, Morrison, Morris, Goldhirsch, Carter, & Meier, 2000). In some instances, discussion of communication is interwoven with reference to the roles and behaviors of the health care providers.

Individual staff and team behavior

The role and behavior of hospital staff both as a team and individually is noted in the research. Healthcare professionals’ teamwork, communication with each other, and attitudes affect patient and family care (Pincombe, Brown, & McCutcheon, 2003). In fact, the centrality of a team approach, teamwork and the need for interdisciplinary care is infused in most of the palliative care literature. Individually, health care professionals’ conduct significantly influenced the behaviors and emotions of patients and families (Pincombe, Brown, & McCutcheon, 2003). Individually, physician compassion (Hodges, London & Lundstedt, 2006) and physician trust were important to family members

(Heyland, Groll, Rucker, Dodek, Gafni, Tranmer, Pichora, Lazar, Kutsogiannis, Shortt, & Lam, 2005). One study of nurses on acute medical wards revealed their perspective of their role in caring for dying patients and families (Thompson, McClement, & Daeninck, 2006). They saw their goal as creating a haven for safe passage, which included helping patients and families transition from a cure to palliation focus (including facilitating decision making and active participation of the patient), advocating for patients to have clear care plans and to have physical needs met, focusing on emotional and psychosocial support for the family, and manipulating the care environment in order to create private supportive space for patients and families during the dying process (e.g. bending the rules about visiting hours, allowing larger numbers of visitors for the patient than are usually allowed on the acute care ward). A comparative study of the hospital and hospice environments described staff at both as having caring beliefs and practices, and using humor and food symbolically in the provision of care (Gates, 1991). Hospice staff practices included greater use of touch, symbolism and ritual related to death and dying. By contrast, research on care of the dying on surgical and medical wards of four hospitals revealed that isolation was a significant characteristic of the patient experience, resulting from minimal contact between nurses and dying patients, distancing and isolating of patients by medical and nursing staff, and increased isolation as death approached (Mills, Davies, & Macrae, 1994).

Additional elements

Some of the topics mentioned above were found in an Australian study conducted in two hospitals using observation and interview techniques to gather data from dying patients, their family members and health care providers (Pincombe, Brown, &

McCutcheon, 2003). The resulting themes from the data included the human factor, the organizational factor, and the environmental factor. The human factor encompasses the patient, the family, and the health professionals. Data revealed the importance of regarding and treating the patient as a person, with dignity, respect, and regard for privacy, needs, and desires. It was noted that patients experience both physical and emotional isolation to varying degrees during the dying process. Families were seen as key participants in the dying process, having significant impact on the manner in which death takes place, the comfort of the patient, and the behavior of staff. The presence or absence of family members both mattered. In regards to staff, the conduct of health professionals both as individuals and as a team had significant influence on patients and families; the degree of teamwork, quality of communication and attitudes affected the situation. The organizational element includes hospital routines and hospital rules. The routine in the hospital (referring to the recurring activities in the daily care of the patient) serves as the backdrop to the experience of patients, family and staff. Hospital rules includes limiting factors such as visiting hours and the importance of staff's sensitivity to disregarding visiting hours in the situation of a dying patient. Finally, the environmental theme in the data includes physical design and layout, as well as ambience. The constant backdrop of noise that characterizes the hospital environment, in conjunction with an ambience of activity and smells that occur in that environment, are not conducive to peaceful dying.

The broader view of the hospital setting highlights the tendency of hospitals to be cure and treatment oriented, with an accompanying resistance to palliative care. Where palliative care is available in the hospital, it may be perceived as a separate entity rather

than integral to overall patient care (Priori & Poulton, 1996). Furthermore, it may be specifically associated with care of cancer patients (O'Neill, O'Connor, & Latimer, 1992). In most hospital settings, provision of palliative care in many hospitals is conducted by a specialist palliative care service or palliative care team (Adelstein & Burton, 1998; Carter, McKinlay, Scott, Wise, & MacLeod, 2002; Demanelis, Keresztury, Emmett, & Moss, 2005; Santa-Emma, Roach, Gill, Spayde, & Taylor, 2002). These elements contribute to the complex context for integrating care of the dying and their families into hospital environments.

Pediatric palliative care

Palliative and end of life care literature specific to the pediatric population is a distinct cluster. Hospital settings that plan to integrate palliative and end of life care into the hospital environment will need to address the subject for all age groups. The pediatric population has some unique needs and issues related to end of life care. These arise from the young age of the patients, great variations in developmental needs and abilities of the children, their limited ability and power to participate in decision making, the related family-centered nature of pediatric care, and the context of pediatric death as a particularly difficult experience in society. However, certain elements of pediatric care, such as the inherent focus on the family due to the young age of the patient, may be helpful to consider for designing high quality palliative care across the lifespan. As with the adult palliative care literature in this review, this discussion does not represent a comprehensive review of pediatric palliative care but rather an overview of the few articles appearing in relation to integrated care.

Although provision of palliative care is often viewed in relation to a life threatening or long term illness, dying in the pediatric population may often also include short time spans for care. A hospital in the US reports that 56% of pediatric deaths occurred in the emergency department, with 72% of the children being previously healthy; the most common causes of death were injury and circulatory events (Vats & Reynolds, 2006). A report from one children's hospital in Australia provides insight into particular elements of pediatric end of life (Ashby, Kosky, Laver, & Sims, 1991). Nearly 60% of deaths occurred in children aged 0-5 years. The four most common causes of death were cancer (27%), congenital abnormalities (19%), sudden infant death syndrome (SIDS) (16%), and trauma (11%). The sudden unexpected deaths were most common, especially for infants. Other pediatric literature further highlights that pediatric end of life involves the death of neonates and infants less than one year old, with children at those ages spending all or many of their days of life in the hospital (Feudtner, DiGiuseppe, & Neff, 2003). Any integration of end of life care into a hospital environment needs to consider the needs of families facing sudden unexpected pediatric deaths as well as those of families facing the trajectory of a longer life-threatening illness. Several pediatric palliative care papers give insight into the needs of families.

A review paper on pediatric end of life care in the intensive care unit summarizes six domains around which care should be organized. These domains include support of the family unit, communication with the child and family about treatment goals and plans, ethics and shared decision making, relief of pain and other symptoms, continuity of care, and grief and bereavement support (Truog, Meyer, & Burns, 2006). These

principles are similar to those seen in adult palliative care, with a more substantial emphasis on the family as the center of care.

Communication in pediatric care is an important component of parents' rating of high quality physician care. Parents gave higher ratings of quality to physicians giving clear information about what to expect in the end of life period, communicating with care and sensitivity, communicating directly with the child when appropriate, and preparing the parent for circumstances surrounding the child's death (Mack, Hilden, Watterson, Moore, Turner, Grier, Weeks, & Wolfe, 2005). The importance of relational components of care is further demonstrated in research on continuity of care.

A paper focusing on the element of continuity of care identified five themes from analysis of interview data (Heller & Solomon, 2005). The first is that continuity builds relationships and promotes caring. Parents seemed to equate the continuity with caring. The second theme is that parents want clinicians to know them and their children as individuals. Being known in this way increases confidence about the quality of care. Thirdly, continuity encourages sharing of expertise and information about the child, both among staff and between staff and parents. This theme encompasses the importance of consistency of information from different care providers to the family, touching upon the importance of communication with the care team. The fourth theme in the analysis is poor continuity of care within and across settings creates confusion and frustration. Finally, the fifth theme is being there through the child's death and parents' bereavement provides great comfort. Each of these distinct themes offers insight into parents' experiences in pediatric end of life care. Viewed in the broader context of service design

for hospital settings, the themes offer compelling data for attending to continuity of care in both the pediatric and adult provision of palliative and end of life care.

Intensive care

The intensive care unit (ICU) setting requires special attention in consideration of integrating palliative and end of life care into a hospital environment. Intensive care, sometimes called critical care, is typically a hospital unit characterized by extensive use of technological and invasive interventions, high-level vigilance and presence of hospital staff, rapid pace, decision making and an intensive focus on rescue and survival.

Although death happens often in the ICU, orientation towards palliation and end of life care requires dramatic shifts in attitudes and interventions (Faber-Langendoen & Lanken, 2000). A study that examined the impact of administrative structure on the ICU setting reveals that ICUs run by surgeons have a strong anti-death orientation, while those controlled by intensive care physicians give more consideration to the utilization of resources and to quality of life issues (Cassell, Buchman, Streat, & Stewart, 2003).

These differences in professional cultures serve to remind that within the overall hospital and medical culture, sub-cultures of different professions and even sub-specialties need to be considered in designing integrated palliative care. They further highlight the influence of administrative organization on clinical care and the ultimate patient and family experience.

Research to address documented deficiencies in end of life care in the intensive care setting identified seven domains for use in ICUs: patient and family centered decision making, communication, continuity of care, emotional and practical support,

symptom management and comfort care, spiritual support, and emotional and organization support for intensive care unit clinicians (Clarke, Curtis, Luce, Levy, Danis, Nelson, & Solomon, 2003). A subsequent study that attempted to incorporate these domains on ICU data entry forms in 15 ICUs in the United States found that symptom management and comfort care were most consistently integrated, while patient and family decision making, communication, emotional and practical support, continuity of care, and spiritual support were not well represented on the ICU documentation (Clarke, Luce, Curtis, Danis, Levy, Nelson, & Solomon, 2004). A separate sub-cluster of research on family conferences has focused on the patient and family-focused communication issues in the ICU setting, documenting specific areas for improvement and recommendations for clinical practice (Curtis, Engelberg, Wenrich, Shannon, Treece, & Rubenfeld, 2005).

End of life care decisions

Withholding and withdrawing life-sustaining treatment

Issues of withholding and withdrawing life-sustaining treatment are relevant across hospital wards but often arise in the ICU. Research in one hospital's general and ICU wards revealed that 74% of patients who died had some intervention withheld or withdrawn before death, with the process often involving a sequence of decisions over several days (Faber-Langendoen & Bartels, 1992). A study that piloted a withdrawal of life support order form for nurses and physicians in the ICU found that while staff found the form useful it did not improve nurses' assessment of patients' quality of dying experience (Treece, Engelberg, Crowley, Chan, Rubenfeld, Steinberg, & Curtis, 2004).

Other research has shown that there is wide variation in the practice of both withholding and withdrawing life support in the ICU (Keenan, Busch, Chen, Esmail, Inman, & Sibbald, 1998; Prendergast, Claessens, & Luce, 1998). A survey of physicians and nurses in five hospitals revealed lack of education about permissibility of withdrawing treatments and an potentially associated finding that four times as many professionals were concerned about the provision of overly burdensome treatment (especially technological interventions) than about undertreatment (Solomon, O'Donnell, Jennings, Guilfooy, Wolf, Nolan, Jackson, Koch-Weser, & Donnelley, 1993).

Do not resuscitate (DNR) orders

Research related to do not resuscitate (DNR) orders has shown that seriously ill hospitalized patients have poor understanding of resuscitation, along with varied interest in participating in the decision making regarding resuscitation (Heyland, Frank, Groll, Pichora, Dodek, Rocker, & Gafni, 2006). The decision making process is further complicated by physicians' frequent lack of awareness of patients' desires regarding end of life care. According to one study, the primary impediment to writing DNR orders in the hospital is the limited extent and depth of the physician-patient relationship (Eliasson, Parker, Shorr, Babb, Harris, Aaronson, & Diemer, 1999). The dying experience of patients with a written DNR order, in comparison with patients having unsuccessful resuscitation attempts, included a greater likelihood to remain in a single unit in the hospital and lower likelihood of dying in an intensive care unit or connected to a ventilator (Weiss & Hite, 2000). The clinical decision to "make a patient DNR" or to facilitate DNR-related decision making with a patient and family is a frequently noted

topic in palliative and end of life care, especially in the context of physician education, communication, and ethical decision making.

Advance care planning

Advance care planning varies in form and frequency across nations and cultures, but it is an integral component of end of life care decision making literature (Nolan & Bruder, 1997). Although minimal literature on advance care planning is included in this review, the topic is mentioned directly or indirectly in many of the reviewed articles. Advance care planning is the process of reflection, discussion and communication of treatment preferences for end of life care (Miles, Koepp, & Weber, 1996). Ideally, patients exercise this process – and any advance directives that result from it – with family, friends, and/or those close to them, as well as their health care providers. The degree to which advance directives are followed in the hospital setting and what explains compliance with these directives has been a topic of some research (Stoeckle, Doorley & McArdle, 1998). In the context of designing integrated care for hospital settings, advance care planning should be an included component of program design.

Ethics committees and policies

The topic of ethics committees and policies was not a focus in the literature reviewed, but articles referred to the existence and relevance of ethics committee for end of life care. One article specifically discusses the development of ethics policies in relation to euthanasia in hospitals and nursing homes (Gastmans, Lemiengre, & de Casterle, 2006). Hospital ethics committees may serve as policy making entities as well as advisory and facilitating entities for complex decision making at the end of life care, often involving withholding and withdrawal of treatment interventions. As such,

integrated care design may include consideration of the roles and functions of an ethics committee within the hospital.

Autopsy and organ donation

Autopsy after the death of a person may be viewed as an essential tool for advancing medical knowledge and monitoring the quality of patient care (Pellegrino, 1996). However, it is a topic that may be difficult for health care professionals to broach with patients and families, before or after the death occurs. Variations in autopsy consent practices in the pediatric setting include parents not being approached about the possibility of autopsy, the treatment team directly asking parents about autopsy, parents broaching the topic themselves, and the treatment team discouraging parents regarding autopsy (Macdonald, Liben, & Cohen, 2006). Consent rates for autopsy on neonates seem to be influenced by the child's diagnosis, the age of the child, and the approach of the consultant (McHaffie, Fowlie, Hume, Laing, Lloyd, & Lyon, 2001). Primary reasons for refusing autopsy according to this study included concerns about disfigurement, a wish to have the child left in peace, and a feeling that autopsy was unnecessary because there were no unanswered questions. Although no literature on adult autopsy practices is included in this review, the pediatric literature illustrates that careful consideration is needed regarding how to integrate communication about autopsy and implementation of autopsy procedures into hospital care.

Organ donation is another process that takes place following the death of the person. Like the topic of autopsy, organ donation is a subject that may be difficult for health care clinicians to broach with patients and families. One study notes that more

hospitals are offering organ donation as part of end of life care for pediatric patients (Kolovos, Webster, & Bratton, 2006). Yet the literature suggests that organ donation policies are fraught with ethical considerations that require careful attention (DeVita & Snyder, 1993; Lynn, 1993). A study of adult organ donation in Spain reports that the strongest elements relating to a family's decision to consent or refuse organ donation on behalf of the deceased are the family's knowledge about the deceased's wishes regarding donation, the family relationship climate, the family's expression of satisfaction with the medical attention received, and the number of relatives present at the consent discussion (Martinez, Lopez, Martin, Martin, Scandroglia, & Martin, 2001). As with the topic of autopsies, the topic of organ donation will require specific attention in creating an integrated care system for dying patients and their families in the hospital setting.

Bereavement

The recognition of bereavement as an integral part of high quality palliative and end of life care has brought attention to the need for hospitals to develop policies and programs for bereaved family members, children and adults alike. Research suggests that support for family members during the patient's last days in the hospital was meaningful in regard to the grief and onset of coping (Kaunonen, Aalto, Tarkka, & Paunonen, 2000). Gaps identified in the care of bereaved family members include a lack of facility for viewing the body privately, lack of staff sensitivity to the possibility of family wanting to be left alone with the deceased, lack of written information about bereavement and lack of follow-up with bereaved family members (Cooke, Cooke, & Glucksman, 1992). One article highlights the importance of having a bereavement policy sensitive to the

possibility that some people, particularly parents of young children, may want to take their loved one home after the death (Whittle & Cutts, 2002).

Hospital based bereavement programs for families following the death of child were more prevalent in the literature reviewed than adult-oriented programs. Programs take various forms and include varied services. Services often include counseling and support groups and are offered for approximately one year following the child's death (DeCinque, Monterosso, Dadd, Sidhu, & Lucas, 2004). One program found that parents appreciated receiving cards, telephone calls and staff attendance at the funeral; parents placed great importance on the hospital's memorial service and staff members' presence at the service; and parents found it difficult to return to the hospital for the memorial service but found it valuable to attend (Macdonald, Liben, Carnevale, Rennick, Wolf, Meloche, & Cohen, 2005). A program specific to infant deaths offers the services of the hospital's professional photographers to take photographs of the deceased infant for the parents (Primeau & Recht, 1994). In another example, a highly structured program titled "The Patterns of Your Life: A Comprehensive Pediatric Bereavement Program" includes critical pathways, education resources and family follow up for up to one year (Nesbit, Hill, & Peterson, 1997). Bereavement services for families in pediatric settings need to consider the needs of children who may have lost a sibling (Heiney, Hasan, & Price, 1993). These examples of bereavement programs for parents demonstrate the diversity of components included in the programs.

Such diversity likely exists for adult bereavement programs not specifically related to the death of a child. One program designed for adults telephoned bereaved survivors, sent letters, sent a "what to expect" sheet, bibliographies of reading resources,

and listings of support services. Evaluation of this program after one year determined that most survivors valued the letters and “what to expect” sheet, while approximately half used the support group listings and few had used the bibliographies (Abraham, Cooley, & Ricacho, 1995). The bereavement literature outside the scope of this review no doubt includes further examples on specific program elements that hospital bereavement services have utilized and evaluated. Some literature in the review referred to the importance of designing services to help staff grieve the deaths of patients, though none of the literature specifically focused on this subject. Hospital-based bereavement services that are integrated throughout a hospital structure need to offer services to children and adults grieving a death under a variety of circumstances.

Preliminary Conclusion

Integrated care for dying patients and their families in the context of hospital-wide services and organization is essentially absent from academic and grey literature. Consequently, this literature review attempts to inform the topic of integrated care by discussing components of hospital services, programs and organization that would serve as the foundation for integration. The overview from the literature provides a conceptual outline for what to consider in the design of integrated care that is focused on the experience of the dying patient and his or her family. The literature demonstrates the complexity of providing end of life care in the hospital setting, both in principle and application.

The results of this review may help identify areas of literature that warrant more in-depth review as efforts to design integrated care advance. The clustering of

information will hopefully make it easier to conceptualize areas of need. In addition, further review of the literature may want to address the extension of integrated care to the junction of hospitals and community, examining what is known about transitions between hospitals and other care settings such as hospices, care homes, and people's private residences.

Expanding on the Preliminary Conclusion: Conceptualizing an Approach to Integrated Care

Due to the limitations of the literature, we will discuss approaches to a model of integrated care informed by the results of the review but developed beyond the bounds of the literature. As noted earlier, the clusters of topics from the review suggest elements and considerations that should underpin an approach to integrating care within an entire hospital. Because the literature does not directly address integration on the hospital level, we will move beyond the elements in the literature to conceptualize how hospital-wide integration might appear.

Recognizing Challenges of the Setting

One of the challenges in creating a dying-sensitive hospital is the need for the hospital to simultaneously care for people with routine or curable conditions who will improve and continue their lives as usual, people with acute conditions that need immediate attention but are likely to get better, and people with life-limiting conditions who are facing end of life either in the short term or in the vague future. It is not always possible to know which outcome a person entering the hospital will face, thus challenging the hospital to create services and systems that can adapt to a particular patient's and

family's situation. Integrated care should create a hospital setting that is flexible and relevant to all patients, including those facing end of life knowingly or not. Such an integration will be particularly challenging in the context of Western biomedicine where death is seen as failure and the discussion of death and dying is frequently uncomfortable for professionals and lay people alike.

The patient and family journey through the hospital system

The journey of patients and families facing end-of-life in the hospital setting begins at admission, occurs throughout the hospital stay, culminates with the patient's death, and continues through the post-death rituals and the process of bereavement. It is important to recognize that the patient's and family's journey includes a history preceding the hospital admission, but this component of the journey will not be addressed in our model due to the focus here on the hospital setting.

Points of entry into the hospital system commonly include the emergency department (also called Accident and Emergency) and direct admission to a hospital ward. The hospital stay takes place on a variety of hospital wards (such as medical, oncology, obstetric, paediatric, geriatric, etc.) and/or specialized units such as intensive care (ICU) or cardiac care (CCU), with perhaps transitional periods in the specialized units or other settings such as surgical suites and surgical recovery rooms. The tremendous variety of settings that a patient and family may experience in the hospital on any given stay requires that all the settings be included in a model of integrated care, even if they are settings not specifically viewed as places of death and dying. All departments and services, including non-clinical services (such as the admissions office,

janitorial and laboratory services), must be viewed as part of the integration. Similarly, all staff members, clinical or other, need to be included in the integration model.

Learning from other integrated care pathways

A model of integrated care may benefit from elements present in successful care pathways: the inclusion of educational components, the presence of a coordinator, and the support of senior staff and management. Hospitals seeking to create an integrated setting may wish to have a dedicated office to oversee this effort both at initiation and for ongoing implementation. Such a dedicated office would serve as a physical reminder of the ongoing need to for integration to exist and improve within the hospital. This central office would have several key functions. It would serve as a central repository of information for how integration was implemented throughout the hospital, allowing comparison, review and learning across areas within the institution. It would work for hospital staff and departments as a resource for designing, monitoring and improving integration over time. Educational initiatives around integration and its related curriculum would be coordinated from this office and serve to provide a cohesive training program across hospital staff and settings. Furthermore, the office could act as a central library of written materials created for patients and families on topics relevant to the pathway towards end of life (this will be discussed further at a later point).

As one would expect, the coordinator for the hospital integration effort would direct this office within the hospital and would report directly to senior hospital management. In order to promote ongoing support from senior staff, regular meetings or other forms of coordination/collaboration would need to take place between the integration coordinator and senior representatives from various departments and services

around the hospital. In addition, inclusion of some line-staff from each department or service in the design and planning of the integration would likely help to garner further staff investment and support towards achieving and sustaining integrated care. The functioning of the integration coordination office would ideally model and parallel some of the key principles of palliative care that integration would seek to offer patients and families: coordinated and collaborative functioning, an interdisciplinary approach, continuity of care, and promotion of dignity.

The imperative of staff education and training

The educational element of an integrated care model would be substantial and ongoing within the hospital setting. As noted earlier, a program of education could be designed and coordinated within an integrated care coordination office in the hospital. This would promote consistency and reduce redundancy in staff education and training. Some educational programs would need to be designed for a “generic” staff audience (such as a presentation about the integrated model to all new employees during their hospital orientation) to introduce people to the underlying principles of the model, its implementation within the hospital, and the implications of its existence for patients and families. Training topics would include those relevant to many staff groups (such as a basic program on communication skills or cultural sensitivity) or to specific staff groups (such as oncology nurses or secretarial staff). Educational interventions would need to take place at regular intervals in order to ensure that new staff members are introduced to the material and veteran staff members are aware of new ways of integration that should be incorporated into patient/family care.

The centrality of communication and communication systems

A sophisticated and sustainable program of integrated care would need to have superb communication and communication systems at its core. There are many types of communication, such as non-verbal, verbal, written, electronic, and visual.

Communication would need take into account a large matrix of people: patients and staff, family members and staff, patients and families and staff, patients and families, staff to staff, staff within departments, staff across departments, and staff within and across disciplines and professions. Cultural awareness and sensitivity would need to apply across all communication. Communication across time (in order to create continuity of care) would also be needed.

In order for the patient and family experience to have a coordinated quality that bridges care by varied professional disciplines, within a variety of wards and/or departments, and across time (either multiple hospital admissions or within one admission), there need to be methods for communication that cross the boundaries of these matrices. On a practical level, this would require collaboration with information systems (computer) designers who would be able to offer creative solutions for complex communications needs across electronic medical records, laboratory reporting systems, clerical information systems, etc. While electronic systems do not replace human interaction and the critical need for hospital personnel to communicate well, any future-oriented program needs to maximize the utility of such tools for achieving institution-wide coordination.

An integration-oriented resource library

In keeping with the communication point made above, an entire library of information brochures may also be helpful for the hospital to develop on topics relevant

to patient and families facing life threatening illness at its various stages. The integrated model would include repeated points along the patient/family experience at which people would be offered the written information (and relevant in-person support as needed). For example, a checklist at the time of admission could include a list of brochures that are available and offer both patients and family members the opportunity to submit the checklist in exchange for a packet of the brochures they request. The same checklist might be available and offered at various points of a ward-stay or at transitions between wards or services. Topics for brochures might include examples such as advance care planning, promoting communication within families, helping children cope with illness and death, funeral planning, and autopsies. As with all of the components of an integrated model, the mechanism for offering and providing brochures would need to be carefully and thoughtfully designed to ensure that patients/families are offered appropriate support to accompany information about sensitive issues. Ideally, there would also be some centralized information system that would track which brochures were requested by a specific patient/family so that (over time and across staffing) there might be some indication of patient/family interests and needs.

Applying palliative care principles to all parts of a hospital

On a conceptual level, a model of integrated care oriented towards patients and families facing life threatening illness and end of life should require the hospital as a whole, as well as each area, department or service in the hospital, to address the central components of high quality palliative care. In regards to the “whole”, there will need to be the aforementioned systems of communication that promote a continuity of information transferral. For example, perhaps an electronic “flag” will appear on a

patient's record if they are identified at the time of admission to have a condition that may lead to their death within the coming year. Or, for example, a patient being seen for the first time at the hospital and meeting this criterion would be automatically referred to social work and spiritual care for initial assessments that would create "tabs" for these clinical services on the front "page" of the patient's electronic record for all future admissions. Other examples of "whole" hospital components might include efforts to address the topics of advance care planning or bereavement. An advance care planning integration effort might include a standardized (across the hospital) set of questions about the availability and offering of advance care planning information for a particular patient that would be used in all admitting and clinical care areas of the hospital to ensure that the subject is addressed and documented. Similarly, perhaps all patient deaths in the hospital would be immediately reported to a central place that would implement services to families and staff (such as information and support) about post-death topics and bereavement, including a follow-up program that would ensure families are contacted at regular intervals for a period of time (e.g. 1 year) following the death.

In applying the model of integrated care to individual areas, departments and services in the hospital, each entity would need to determine how each of the palliative care principles can and should be incorporated into practice. The relevance of each element of high quality palliative care to a given area or service will vary throughout the hospital, as will the methods by which these areas or services respond to relevant needs. For example, nursing services may determine that a nurse's intake interview may address the topic of pain and symptom assessment by asking the patient to respond to questions about specific symptoms, including rating the intensity and impact on the patient.

Simultaneously, the issue of sensitivity to pain and symptoms may be addressed by the janitorial service by creating a list of questions posted by patients' beds that invite patients to notify janitorial staff if they have a condition or symptom that needs specific attention, such as sensitivity to light (so cleaning staff will take this into account as they turn on lights or open window shades when they come to clean the room), or sensitivity to certain smells (such as cleaning products). These examples are used to illustrate that the main principles of high quality palliative care may be applied and considered in ways not traditionally considered in the hospital setting.

Final Comments

The details that would eventually result in an integrated care model at a given hospital may come from a process of systematically applying core principles of high quality palliative care to each and every area of the hospital, whether it be a clinical service, a department, or a physical area in the institution. By calling upon each service and department to rigorously examine how the principles of palliative care could be brought to bear on work and policies, a hospital-wide program of integration would emerge. This is a complex and challenging program development process, but one that may ultimately create an integration model that can be applied across settings without needing to be designed anew at each hospital.

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Appendix 1: Search terms used for electronic databases

Name of Database	Terms searched as Keyword / MeSH* combinations
<i>British Nursing Index</i> (BNI)	Integrated care OR care pathways OR continuity of care OR hospitals AND end of life care OR care of the dying OR post mortem care OR (bereavement or grief) OR (terminal care or terminal illness) OR palliative care ALL AS KEYWORDS
<i>Cumulative Index to Nursing & Allied Health Literature</i> (CINAHL)	Integrated care OR care pathways OR continuity of care OR hospitals AND end of life care OR care of the dying OR postmortem care OR (bereavement or grief) OR (terminal care or terminal illness) OR palliative care
<i>Evidence Based Medicine</i> (EBM) Reviews	Integrated care OR care pathways OR continuity of care OR hospitals AND end of life care OR care of the dying OR post mortem care OR (bereavement or grief) OR (terminal care or terminal illness) OR palliative care
<i>EMBASE</i>	Integrated care OR care pathways OR continuity of care OR hospitals AND end of life care OR care of the dying OR postmortem care OR (bereavement or grief) OR (terminal care or terminal illness) OR palliative care
<i>PubMed</i>	Integrated care OR care pathways OR continuity of care OR hospitals AND end of life care OR care of the dying OR postmortem care OR (bereavement or grief) OR “terminal care/organization and administration” OR palliative care

*MeSH (Medical Subject Headings: a specific classification system used by the database)

Appendix 2: Number of articles identified in each electronic data base

Name of database	Number of citations from original search	Number of titles selected	Number of titles after duplicates removed ()	Titles rejected for abstract selection	Number of abstracts selected
<i>BNI</i>	109	66	30 (36)	19	11
<i>CINAHL</i>	642	181	162 (19)	88	74
<i>EBM Reviews</i>	87	14	12 (2)	9	3
<i>EMBASE</i>	391	152	59 (93)	52	7
<i>PubMed</i>	2439	289	208 (81)	99	109
Totals:	6828	702	471 (231)	267	204

Appendix 3: Grey literature documents

- National Institute for Health and Clinical Excellence (NICE) guideline for cancer services: *Improving Supportive and Palliative Care for Adults with Cancer* (March 2004). Identified via the Guidance section of the NLH website.

- *Clinical practice guidelines for quality palliative care*. Brooklyn (NY): National Consensus Project for Quality Palliative Care (2004).

- Department of Health documents of limited relevance:

- *Families and Post Mortems: A code of practice* (April 2003)
- *NHS Chaplaincy - Meeting the Religious and Spiritual Needs of Patients and Staff* (November 2003)
- *When a Patient Dies: Advice on developing bereavement services in the NHS* (October 2005)

These documents were identified via the NLH website's Specialist Libraries.

- A Protocol & Care Pathway titled *Care of the Dying* (South Manchester University Hospitals NHS Trust) was mentioned on the NLH website but with no accompanying document. It was identified via the website's Protocol & Care Pathway Specialist Library. No literature is available about the pathway except for one article (identified in the academic literature review) that addresses the role of the clinical facilitator in advancing the pathway.

- Liverpool Care Pathway developed by the Royal Liverpool University Trust and the Marie Curie Centre Liverpool (see website <http://lcp.mariecurie.org.uk/>).

- Palliative Care for Advanced Disease (PCAD) clinical pathway documentation is available on the website www.stoppain.org. The pathway is also discussed in the academic literature.