Is There a Place for Artificial Hydration in End of Life Care?

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Abstract

The purpose of this project is to thoroughly explore research and best practice guidelines related to the administration of artificial hydration in end of life care for patients diagnosed with cancer. More specifically, this project will address the question: Is there a place for artificial hydration in end of life care? Upon reviewing the information included in subsequent sections, nurse practitioners will acquire the following: an appreciation of the historical context of hospice palliative care, a thorough understanding of the pathophysiology of the dying process, knowledge of the burdens and benefits of artificial hydration, an understanding of the psychosocial aspects of death and dying, knowledge of ethical principles in relation to end of life care, as well as tools to communicate effectively to patients and family members during one of the most critical phases of their life.
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CHAPTER 1
Background and Need

Introduction

“Dying is a normal part of living. No single way of dying is ideal, yet there are some general principles that can guide us in providing care for the dying” (McCormick & Conley, 1995, p. 237). The 21st century has brought a resurgence of interest in palliative and end of life care not only in Canada but also the world. Policies have been written and money has been allotted in order to ensure quality care for those who are experiencing the end of their lives (BC Ministry of Health, 2006). Tertiary care centres may have a palliative care ward, and free standing hospices are present in most provinces across Canada. According to the Canadian Hospice Palliative Care Association (CHPCA, 2006) some individuals are opting to die at home which necessitates quality end of life care twenty-four hours per day, seven days per week in people’s homes with appropriate support and professional care. Consequently, the reservoir of information and options available to individuals at the end of their lives has empowered clients to take ownership and make choices for their health care.

Over 20 years of work experience in a variety of settings including: acute, tertiary, rural and remote, hospice and home care, has provided the author of this project the opportunity to learn about the specific needs and challenges of each care setting in relation to care for the dying. For example, it is not unusual for families and caregivers to suddenly realize that their loved one is dying when they can no longer eat or drink, or they refuse to do so in the days prior to their death. This acknowledgement of their loved one’s approaching death often results in many questions to the health care professional regarding options for treatment and requests for hydration. A common discussion that often occurs relates to how best to meet the nutritional and hydration needs of their loved ones once a terminal diagnosis has been
discussed, particularly as the client’s condition declines. This review of literature was conducted because the author of this project believes that hydration and end of life care are practice aspects she might influence as a nurse practitioner in primary care practice.

**Historical context of hospice and palliative care**

Modern hospice care was initiated by Dame Saunders in London, England in the 1960’s. St. Christopher’s was the first research and teaching hospice established to care for the dying, provide home care and family support throughout illness and bereavement care (Saunders, 1996; CHPCA, 2002a). It was founded on the following principles: care for the ‘whole’ person including pain and symptom management, attention to spiritual/emotional and mental needs, as well as care for family and the use of a multidisciplinary team in order to provide that care (International Association of Hospice Palliative Care, 2008). Some aspects of this care are not always available in mainstream medicine, and community-based hospice provides care for those who are terminally ill in the community. The focus of hospice care is comfort and symptom management compared to treatment, cure and discharge, which is the norm in an acute care facility. Death is accepted as normal and the transition from life to death; as well as concern for the patient and family, become the focus.

It is the philosophy of many facilities that provide hospice care not to provide hydration at the end of life because cessation of intake is part of the natural dying process (Ellershaw, Sutcliffe, & Saunders, 1995). Acute care hospital practice will provide hydration in order to reverse dehydration if evident, quite possibly to avoid difficult conversations with patients/family members and/or because emphasis is on the curative role (Andrews, Bell, Smith Tischler, & Veglia, 1993; Burge, 1993; Burge, 1996; Soden, Hoy, Hoy & Clelland, 2002; Viola, 1997). Experiences with palliative patients receiving home care is varied some
request artificial hydration and receive it, while others do not. There is a perception and misunderstanding that in a hospice care setting acceptance of death as normal is interpreted as ‘nothing being done’. However Hayslip and Leon (1992) state that “hospice care is very aggressive regarding the dying person’s physical or emotional state, for example, in treating pain, nausea, vomiting, constipation, infection, edema, pneumonia, depression, or anxiety. Moreover, hospice encourages those persons who desire control over their lives to continue to make decisions about life and death” (p.10).

In Canada, Dr. Balfour Mount, a Canadian urological surgeon based in Montreal, visited Dame Saunders at St. Christopher’s and is credited with the initiation of palliative care in Canada in 1975. The term ‘hospice’ had negative connotations such as “destitution and poverty” in the French language, thus, Dr. Mount chose to use the word ‘palliative’ in referring to care of the dying (Syme & Bruce, 2009, CHPCA, 2002a). The word ‘palliative’ comes from Latin meaning ‘to cloak or cover’ (Thomas, 1982). Dr. Mount established a new palliative care service at the Royal Victoria hospital in Montreal. That same year, a similar palliative care program was established in Winnipeg at the St. Boniface General Hospital by Dr. Henteleff. Dr. Mount played a pivotal role in making palliative care universally accessible to all Canadians (Hamilton, 1995). These Canadian programs became models for the World Health Organization and hospitals in more than 30 countries, to integrate hospice concepts into health care systems (Hamilton, 1995). Palliative care programs were developed primarily in larger health care institutions, whereas, hospice care developed within the community. In order to recognize the convergence of hospice and palliative care as one movement, the CHPCA developed the term ‘hospice palliative care’ (2002a, p.v). This was done in order to unite both movements; however, the roots of each should certainly be
recognized and acknowledged. “Hospice palliative care can and should cherish its roots in community-based philanthropy at the same time as it strives for clinical excellence” (Syme & Bruce, 2009, p. 23). Questions arose regarding whether or not combining the terms is helpful, and suggest the use of another term “end of life care” (p.23). However, this term was introduced primarily in the literature in relation to geriatric care. During the 2002 CHPCA meeting, there was discussion regarding use of this term, but members were divided 50:50 and no consensus was reached (Downing & Wainwright, 2006). The literature tends to present one or any of these terms in published format.

Over the past 10 years there has been considerable growth in palliative care. A case in point is British Columbia, where the Ministry of Health developed a provincial framework for hospice palliative care with integration of palliative care indicators (BC Ministry of Health, 2006; Syme & Bruce, 2009). All documentation regarding palliative care in the Northern Health Authority (NHA) changed the wording to ‘hospice palliative care’ in 2008. The specialization of palliative care in mainstream hospitals, hospices, and home care for those who are dying provides individuals with choices about where they would like to die. Today, some tertiary care settings have palliative care wards, while other facilities have a palliative care team for referral and consultative services. Over time, expertise in the area of palliative care has resulted in improvements in symptom management, as well as recognition of national standards for palliative care in the home (CHPCA, 2002b; CHPCA, 2006; Downing & Wainwright, 2006; NHA, 2008).

The development of hospice palliative care in Canada has informed health care providers of options for care within a particular health setting or province. In Prince George, British Columbia, there is the presence of a freestanding 5-bed hospice, a palliative care nurse
consultant for the Prince George Regional Hospital, and the provision of care through Home and Community Care services (H&CC). H &CC offers home support, as well as care and assessment provided by a social worker, occupational therapist, and/or physiotherapist. Home care nurses in Prince George are available from 0800 a.m. – 9:30 p.m., 7 days per week. There are three other palliative nurse consultants across NHA, as well as a regional interdisciplinary consult team for the support in management of palliative patients (NHA, 2005).

The H & CC program in Northern Health, Prince George, has built into its program an opportunity for the home care nurse to complete a ‘bereavement’ visit with the family of the patient enrolled in hospice palliative care. It is possible for the home care nurse to attend the funeral of a patient for whom he/she has cared. During the bereavement visit the home care nurse often leaves information for the family regarding grief and bereavement programs offered through Prince George Rotary Hospice House (PGRHH). At the hospital there may or may not be input from chaplaincy services, and/or social workers, as well as the palliative care consultant. There is no bereavement care in terms of organized programs at the Prince George Regional Hospital (PGRH). PGRHH provides bereavement programs for children and adults. The protocols and context of hospice palliative care within a local jurisdiction is important information for the practitioner. This then enables the practitioner to provide the best care using local resources to care for his/her patient.

**Question of inquiry**

In order to better understand current trends in end of life care and determine if gaps in the literature exist, a review of literature was undertaken. To guide this review, the project was formulated around the following question of inquiry:
1. Is there a place for artificial hydration in end of life care?

Hydration often becomes an issue of immense personal angst and a dilemma for both the individual and the family in that the patient is dying and food and fluids may not be helpful during the process of dying. The dilemma becomes more profound when there is a desire is to prolong life because where there is life there is hope. The education process of becoming a nurse practitioner (family) enables one to practice and care for individuals from cradle to grave. As the population is aging and chronic diseases are abundant, the importance of caring for patients during their last days on earth is one of privilege and responsibility. It is a privilege to care for someone as they face their last days on earth, which results in the responsibility to ensure that that care is up to date, evidenced based, multidisciplinary, within one’s scope of practice, and congruent with the goals of the individual and family.

Significance of the project

The literature indicates that only 10% of the population experiences sudden death (Ellershaw & Ward, 2003). The rest of the population tends to have chronic disease and lives with disease until death. What does this mean for clinical practice? Nurse practitioners need to be aware that the majority of patients will have chronic disease and at some point will require hospice palliative/end of life care. For example, as a family nurse practitioner student, this writer spent a clinical rotation in a geriatric assessment and treatment (GAT) unit in an acute care setting, as well as a rotation at an urban primary health care clinic. Each setting was unique with its own set of challenges and complexities. Reviewing the issue of end of life care, it was noted that four of the patients seen and assessed in the GAT unit have since died within the past six months. This information was observed from obituaries in the local newspaper. In the geriatric setting, one of the patients, in collaboration with their
family, did sign a ‘do not resuscitate’ (DNR) directive and a discussion of advance planning took place in the fall, prior to the individual’s death in March 2009.

In the urban primary health clinic, there were at least two patients that were seen who had pre-existing comorbidities and experienced functional decline over the previous 6 months. Of these latter patients, one explicitly mentioned that he felt his physician did not listen to his concerns and that he would die soon. In this case, the nurse practitioner student allowed the patient to vent during a lengthy visit (> 1 hour), and encouraged him to express his concerns with both the specialist and physician in his upcoming appointments the following week. The other patient had several visits due to distressing symptoms. After a discussion with one preceptor, a referral was sent to the patient’s specialist to specifically clarify prognosis, and encourage the use of palliative care principles for symptom management. Chapter 2 provides the reader with a review of current literature associated with artificial hydration, ethical considerations, and pathophysiology associated with the dying process. Finally, therapeutic communication considerations associated with end of life care are discussed.
CHAPTER 2

Review of Literature

Knowledge of the pathophysiology, psychology, communication needs, and review of ethical considerations of artificial hydration as part of end of life care provides the context for this review of literature. A literature search utilizing electronic sources reviewed the following databases: CINAHL, DARE, MEDLINE, COCHRANE, SAGE, PSYCHINFO, and TRIP. The following key words were used in various combinations: palliative, hydration, rehydration, artificial hydration, dehydration, thirst, and end of life care. In CINAHL, using limits of ‘full text’ and ‘English language’, the key word combinations and results are as follows; artificial hydration & end of life care, (four results); thirst and end of life care, (one result); dehydration and end of life care; (three results), and dehydration and palliative care (61 results). PSYCHINFO yielded a total of 19 articles from the various searches. Evidence-based medical journal reviews yielded 13 articles. SAGE, with the same key word combinations as CINAHL, provided 21 articles to review. MEDLINE with the same combinations for each search found 101 articles. Utilizing the terms ‘palliative’ and ‘dehydration’ in OVID Medline from 1950 on, 431 articles were retrieved.

The following websites were searched in order to find evidence-based clinical practice guidelines; nursing websites, Canadian Medical Association (CMA), National and Provincial guidelines for Hospice Palliative care, as well as Joanna Briggs, the Registered Nurses Association of Ontario, National Clearing House, and websites found in one course textbook (Melnyk & Fineout-Overholt, 2005). After applying the inclusion criteria of “full-text” and “English language” to the searches, a total of 90 articles were reviewed for this project. The review of literature has been organized into four major sections: Pathophysiology of death
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and dying; Psychology of death and dying, Therapeutic Communication in death and dying; and Ethics and death and dying. The Ethics section specifically addresses artificial hydration, as a major theme for discussion in Chapter 3.

Pathophysiology of Death and Dying

Anorexia-cachexia syndrome

The health care professional needs to be keenly aware of the pathophysiology of various diseases, and in particular, changes that occur in an individual prior to his or her death. The inability to recognize changes may mean that the individual, as well as the health care professional, is not aware of imminent death resulting in missed opportunities for resolution of certain matters and a chance to say goodbye.

One of the most obvious symptoms associated with cancer in many patients is anorexia-cachexia syndrome that often results. Anorexia-cachexia syndrome affects up to 80% of patients with advanced cancer (Harman, 2009). This syndrome results in weight loss, anorexia, tissue wasting, weakness, impaired immune function and poor physical performance (Camps, Iranzo, Bremnes & Sirera, 2006; Esper & Harb, 2005; Laviano, Meguid, Inui, Muscaritoli, & Rossi-Fannelli, 2005). This, combined with anemia (which is often present), results in limitations in physical activities and the inhibition of protein synthesis. When anorexia is combined with cachexia: “it acts synergistically to impact on patients’ morbidity, mortality and quality of life” (Laviano et al., 2005, p.159). According to the literature, 50% of patients express abnormalities of eating behavior at the time of initial diagnosis and in those with terminally ill cancer, the incidence increases to 65% (Camps et al., 2006 Laviano et al., 2005). Patients with no weight loss at the initial cancer diagnosis had better survival rates, fewer treatment complications, and a better response to
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chemotherapy than those with weight loss (Camps et al., 2006 Laviano et al., 2005) present the optimal treatment is to cure the underlying cancer. When this is not possible, a number of approaches need to be considered. The expertise of dieticians, coupled with pharmacotherapies such as progestins, cannabinoids and corticosteroids are possibilities (Camps, Iranzo, Bremnes & Sirera, 2006; Esper & Harb, 2005; Harman, 2009; Laviano, Meguid, Inui, Muscaritoli, & Rossi-Fannelli, 2005). There is no cure for anorexia-cachexia syndrome, and the management is challenging. The focus of treatment is to improve the quality of life for the individual and to look at his or her goals for treatment. The presence of anorexia-cachexia syndrome in an individual may affect their mortality.

Functional decline

Work done by Teno, Weitzen, Fennell and Mor (2001) discovered that patients with cancer experienced a rapid decline in functional ability about five months prior to death. Patients with illnesses such as chronic obstructive pulmonary disease, congestive heart failure, and diabetes mellitus experienced functional impairments a year prior to death, and then had a gradual decline in functional ability. This observation is in keeping with not only the time frame for when a person is deemed palliative (about 6 months prior to death) but also with subsequent changes that are observed in patients: “...rapidity of functional decline may serve as a cue to the physician, patient and family that the person is dying” (p. 461). The clues then to the practitioner are the presence/absence of anorexia-cachexia syndrome, and the amount of functional decline in determining the months prior to death and dying.
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Cycle of events surrounding death

There is a fairly well-documented cycle of events that occur when death is imminent, usually due to gradual multiple organ failure in those with a palliative/cancer diagnosis (Stevenson, Abernethy, Miller, & Currow, 2004; Swanson & Cooper 2005). This results in a gradual decrease of function in every body system culminating with no palpable heart beat, no respirations, and absence of the corneal reflex (Downing & Wainwright, 2006; Emmanuel, Ferris, von Gunten, & Von Roenn, 2008). The physical body, as we know it, will change and progress from warm to cold, from a living to non-living state, where the person is unable to respond ever again. According to the College of Registered Nurses of British Columbia (CRNBC), it is within a registered nurse’s scope of practice to pronounce death (CRNBC, 2007). The details of the pronouncement are usually up to the place of employment. Minimally, there is documentation of absence of a heartbeat, absence of respirations, for a full minute for each, as well as inspection of the eyes, for fixed and dilated pupils which are non-reaction to light (Charlton, 1996; Downing, 1998). Charlton (1996) also suggests that initially the examiner will note pallor of the face and lips, relaxation of the facial muscles which results in an opening of the mouth, and open staring eyes. Charlton further suggests that a complete physical exam should be completed preferably in private, including examination of carotid, radial and femoral arteries. Observations for respiratory effort as well as noting a dry and cloudy appearance to the cornea, absence of corneal reflexes and loss of eyeball tension. At some point after death (from 3 to 8 hours), the body will exhibit signs of hypostasis which include purpuric death spots as well as the onset of increasing muscle stiffness, and decreasing of body temperature, which may not occur until up to 8 hours after death. Charlton (1996) states that: “The diagnosis of death is made by
excluding all possible signs of life” (p.957). Moneymaker (2005) in a patient information sheet regarding the dying process, under active dying and death, concurs with Charlton’s (1996) statements, as well as adds the following: secretions may ooze from the nose and mouth, muscle jerking or twitching may occur, tears may seep from the eyes, there may be vomiting, and loss of bowel or bladder control. The palliative literature states that many people wish to be present when a health care professional pronounces the death of their loved one, as it may be the final stage of the dying and grieving processes, and a chance to say one last good bye before the body is taken (Downing & Wainwright, 2006; Emmanuel, Ferris, von Gunten, & Von Roenn, 2008).

Cause of death

In those who have been diagnosed with cancer, the actual cause of death is attributable to: infection, organ failure, infarction, hemorrhage and carcinomatosis (Downing & Wainwright, 2006). Interestingly, the cause of death in those who have terminal illness is not a result of malnutrition and/or dehydration. Abdel-Karim, Sammel, and Prange (2007) looked at the cause of death at autopsy in an inpatient hospice program in Texas and discovered that the primary cause of death, other than the cancer, was pneumonia. This was followed by hepatic and renal failure, and then ischemic heart disease. A few patients died directly from effects of the cancer, i.e. tumour burden and brain metastases, while three died from pulmonary emboli.

In conclusion, all the factors involving the pathophysiology of death and dying need to be considered when thinking of utilizing artificial hydration in end of life care. Knowledge of the impact of the anorexia-cachexia syndrome in the lives of individual’s lives, awareness of functional decline, and knowledge of impeding death will all be factors to consider prior to
presenting and/or initiating artificial hydration for patients who are not yet dying. More important, one should always consider the impact of artificial hydration on the quality of life of the individual at the end of life. These discussions are challenging when individuals are observing the gradual decline and impending death of their loved one.

**Psychology of Death and Dying**

The literature indicates that there is work involved with the dying process and with death itself (Byock, 1996, 2002; Crang & Muncey, 2008; Downing & Wainwright, 2006; Kübler-Ross, 1969; McCormick & Conley, 1995). As an individual comes to terms with his/her imminent death there are possibilities for growth and completing the work that is involved with dying. This work may involve some of the following: bringing closure to life, embracing individual spirituality, finding meaning in suffering, coming to terms or exercising forgiveness, either to another or from another, and many other tasks (Byock, 1996; McCormick & Conley, 1995). Byock (1996) has documented developmental tasks that are believed to be completed during this time frame (see Appendix A). This extensive list of tasks and developmental landmarks includes considering practical issues such as completing worldly affairs, but also more transcendental ones such as developing a new sense of self, surrendering to the unknown, and finally ‘letting go’.

Approximately 90% of individuals have some prior knowledge that they are dying, which means that the work of dying does have potential to be completed in as much as the individual is able and/or willing (Emmanuel, Ferris, von Gunten, & Von Roenn, 2008; Higginson & Addington-Hall, 2004). Physical symptoms are only part of management of care during end of life. There are other aspects to complete the task of dying. It is a time and opportunity for the individual to gradually accept that their time on earth is coming to a close
and that tasks of reconciliation, forgiveness, and hope, are completed. This is not easy work, and for each individual a unique time to process and work through some of the tasks of dying is required. Some individuals, because of life choices and/or circumstances, will be hesitant to embark on some of the tasks and may need some input from loved ones and from the interdisciplinary palliative care team.

Fortified with this knowledge, the health care professional needs to ensure that he/she is aware of these tasks, and encourage the individual to think about or spend time accomplishing them. This is no easy job. It will require great skill and understanding from the health care professional in order to allow the person to work through the following: changes in his/her physical body, gradual dependence on others, and slow recognition of imminent death and a turning towards others and thinking of his/her life in terms of coming to completion. Work by researchers such as Kübler-Ross (1969), Byock, Caplan, and Snyder (2001) and Saunders (1996) have documented work suggesting that death is the final act of growth in an individual.

Spirituality and death

Awareness by the health care professional of tasks mentioned in the previous section provides an understanding and context; particularly in instances where a patient requests invasive or intensive treatment at end of life, when their goals may not have been completed. This is the time that the conversations and communication between the patient and palliative care team are crucial, as goals of treatment can be decided and everyone is working towards a common goal. If the discussions do not occur, the patient can be left feeling like their need to complete their work of dying will not be done. This may lead to frustration, anger and, perhaps, exacerbation of physical symptoms.
Spirituality can be defined as finding purpose and meaning in life which is a very important part of care for palliative patients (Duggleby & Berry, 2005). Holloway (2006) suggests it is not so much the spiritual dogma of beliefs for the individual but the ability of the nurse to attend to the individual regardless of their spiritual beliefs, and acknowledge particular rituals and practices that enable humans to come to terms with death and dying. Religious and spiritual beliefs are utilized by those diagnosed with a life-altering or life-limiting illness. This spiritual belief often provides a sense of hope and a greater meaning of the illness in relation to life for individuals. It can be used as a frame of reference for those who are trying to make some sort of meaning out of their suffering, or as their life ends.

Of interest is a study by True et al. (2005). They examined spiritual beliefs between African American and Caucasian patients with cancer and their use of spirituality, coping mechanisms, and preferences for care at end of life. The researchers found that the use of spiritual coping was strongly associated with preferences for CPR and hospitalization in near-death situations. This was seen more in African American patients with cancer and their families. This is an important finding, as it may help the health care professional communicate with African American patients and provide background for why certain choices are preferred. This knowledge provides context and understanding in how patients make decisions at the end of life.

Factors influencing death and dying

A study by Schroepfer (2007) investigated critical events in the process of dying and examined the possibilities for physical and psychosocial suffering. The following were determined to be critical events: "perceived insensitive and uncaring communication of a terminal diagnosis; experiencing unbearable physical pain; unacknowledged feelings
associated with chemotherapy or radiation treatment; and, dying in a distressing environment” (p.136). According to the study, when any of these critical events occurred, the individual wished for or considered hastening their death. The individuals were able to articulate the types of things which helped to lessen the impact of these critical events.

Ensuring that pain is managed well is of tremendous importance to those facing death. The manner in which a ‘terminal diagnosis’ is given to an individual can be tempered in its delivery and in the assurance of the practitioner of the commitment to continued care in the midst of approaching death. The importance of place of death as well as the acknowledgement and importance of listening to the individual regarding his/her choices for radiation and/or chemotherapy option are paramount in order to assist the individual in achieving their goals at the end of their life.

This qualitative study by Schroepfer (2007) is reminiscent of a small qualitative study done by McCormick and Conley (1995). McCormick and Conley interviewed six patients having a life-threatening illness and noted the following at completion of their qualitative study: “It is important that physicians take time to listen to their patients’ stories and to ask about their thoughts, feelings, and concerns throughout the changing circumstances of treatment care (p.239)”. Both these studies emphasize the importance of communication.

Perkins, Booth, Vowler, and Barclay (2008) found that: emergencies, pain and improving doctors’ abilities to understand patients were identified by patients and caregivers as top research priorities. This is similar to the findings of Schroepfer (2007) and McCormick and Conley (1995).
Health care professionals need to always be reminded that death is part of life, as without death, there is no meaning in life. The disciplines of philosophy and theology are often utilized to help explain the meaning of life, however many health care professionals recognize that one of the difficulties in caring for the dying requires facing our own mortality.

The health care professional must approach the use of hydration with caution in order to recognize the importance of the spiritual, emotional and psychosocial aspects of dying. If possible, the health care professional can encourage closure for some of the difficult tasks and engage in understanding and dialogue with patients who are in the last months of their lives. A willingness to enter into discourse and recognize that a patient's inability to come to terms with the emotional/spiritual work may cause an individual to beg for a treatment in order to prolong life, and/or to dismiss the cruel march towards death.

**Therapeutic Communication in Death and Dying**

*Essentials of effective communication*

The therapeutic relationship is the basis of care and communication between the health care professional and the patient. It is this relationship that marks care during the continuum of life. Published literature states that health care professionals can facilitate communication by: asking open ended questions, allowing sufficient time for patients to speak, and the use of empathy (Downing & Wainwright, 2006; Duggleby & Popkin, 2006; Evans, Tulsky, Back & Arnold, 2006; Mount, 1998; Surbone, 2008). Tulsky (2005a) postulates that, “Trust, the confidence that one’s health care provider is acting unfailingly in one’s interest, is fundamental to all effective medical care, particularly at the end of life. Uncertainty characterizes all medical decision making, and physicians must help patients manage it” (p.
Trust is a key component in the facilitation of effective communication and also is involved in the initiation of discussions about end of life care in terms that the patient and/or family member can understand (Peden, Tayler & Brenneis, 2005). As Tulsky (2005a) points out, families and patients may be overwhelmed by the number of choices regarding medical care that precedes death ranging from aggressiveness of treatment to the site of care. These struggles may result in conflict and dissatisfaction with the medical team. The importance of determining outcomes of care is a crucial point in end of life or hospice/palliative care.

Meaningful communication between patients, families and health care professionals often occurs during transitions experienced by the patient. Duggleby and Berry (2005) in their work on transitions in palliative care state that, “Examples of transitions experienced by palliative patients and their families are: from cure to comfort, related to loss, between care settings, and often psychosocial and spiritual in nature” (p. 425). Evans, Tulsky, Back, and Arnold, (2006) confirm that many transitions occur for patients when diagnosed with cancer. There may be large transitions such as; initial diagnosis, progression of the cancer, and referral or involvement of hospice. Smaller more personal ones may be; hair loss, insertion of a central line, or needing assistance with personal care. These transitions require the patient to adjust and grieve if loss occurs with a transition, as well as cope with emotions such as anger, sadness and anxiety.

The words ‘palliative’ care or a referral to hospice or a palliative care team, may, to some individuals signify their immediate death, instead of recognizing a shift in care. This shift from curative to palliative is when the individual may come to terms with their approaching death. Most programs declare, and/or involve hospice or palliative care when the health care professional (generally a physician) believes the individual has about 6
months of life remaining. In B.C., once a person has been deemed ‘palliative’ they are registered with the palliative drug program, and registered for hospice/palliative care. This registration ensures that they are eligible for free drugs, equipment and services from home and community care (BC Ministry of Health, 2006).

Trust, the ability to initiate discussions regarding death and dying, use of open-ended questions, empathy, active listening, expertise and respect are all important skills for use by health care professionals (Evans, Tulsky, Back, & Arnold, 2006; Mount, 1998; Surbone, 2008; Tulsky, 2005a; 2005b). Tulsky (2005b) states that work has been done in order to enhance communication skills of physicians and nurses by use of small group training sessions, role play and standardized patients. Enhanced learning can lead to more effective communication by physicians and health care providers. In all patient/provider communication, the health care professional needs to be cognizant that patients have very individual desires for information, how much, how often, and what they wish to hear or not to hear. This is vital information and requires keen active listening skills. The importance of consistency and openness, the need for specific information to care for the patient, and the value of separate discussions with patient and caregiver have been identified by patients and caregivers as priorities in studies regarding communication (Downing & Wainwright, 2006).

There are several different ways for the health care professional to ensure that communication is effective and helpful to the patient. The Australian Medical Association published a set of clinical practice guidelines for communicating prognosis and end of life issues with adults in advanced stages of life-limiting illness, and their caregivers (Clayton, Hancock, Butow, Tattersall, & Currow, 2007). This document provides the health care professional with tools to utilize in communicating with those who are in the stage of the end
of their life. As the practitioner becomes more comfortable with the initiation of difficult discussions, a simple acronym PREPARED is proposed. This includes the following aspects of communication: Prepare for discussion, Relate to the person, Elicit patient and caregiver preferences, Provide information, Acknowledge emotions and concerns, Realistic hope, Encourage questions, and Document (Clayton, Hancock, Butow, Tattersall, & Currow, 2007). Evans, Tulsky, Back and Arnold (2006) suggest several methods that can be utilized in the expression of empathy; use of the acronyms SOLER (non verbal empathy; sit Squarely, Open toward the patient, Lean forward, Eye contact, Relaxed posture) and NURSE (expressions of empathy; Name the emotion, Understand the emotion, Respect the patient, Support the patient, Explain the emotion) as well as ‘ask-tell-ask’ and ‘hope for the best, prepare for the worse’. These are all helpful methods of enabling the health care professional to deal with difficult conversations and ensure that the patient’s needs are being met, hope remains, and realistic, accurate information is conveyed.

Barriers to effective communication

Barriers to effective communication are the time constraints of health care professionals. Discussions with a patient and family regarding death and dying cannot be rushed, time is required for individuals to process information, and express emotions. Often, conversations need to be repeated over time in order for the individual to understand and have their questions asked and answered. Larson and Tobin (2000) recognize that; “The structure of the medical care system discourages productive end of life conversations. These are not a routine part of care, and clinicians rarely have a structure for discussing end of life issues within their busy schedules, coordination of these conversations becomes more necessary as the illness progresses…” (p. 1574). Wittenberg-Lyles, Greene and Sanchez-Reilly (2007)
suggest that health care students be exposed to these conversations and experience the tension that results from discussions of length and quality of life. These tensions are real and exist when working with patients and families. Other barriers to effective communication result from the health care professional being unwilling to cause pain and give bad news, lack knowledge in how to deliver bad news, viewing death as something to be defeated, and anticipating disagreement from the patient or family (Larson & Tobin, 2000). Other barriers to communication come from patients; who are unwilling to express fear, feel anger, loss, or fear death itself. Men often experience more difficulty discussing their feelings and personal issues (Mount, 1998).

The patient’s cultural prohibitions may also result in the inability or unwillingness to discuss death and dying (Larson & Tobin, 2000; Searight & Gafford, 2005). Surbone (2008) indicates that cultural sensitivity, cultural awareness and cultural competence are interrelated in the clinical context. Rather than slotting individuals into what the practitioner believes is their cultural heritage, it is more important to ask the patient about their cultural background, including religious beliefs. Then the health care professional needs to ask how the individual wishes to be informed about their health information. Asking rather than assuming, ensures that the practitioner is culturally sensitive and competent. Trust, time, therapeutic communication skills including active listening, and empathy are all essential in dealing with our dying patients.

*Communication and prognostication*

Downing and Wainwright (2006) provide lengthy discourse regarding the determination of prognosis. Prognosis is a time-frame, not a one-time pronouncement that is adjusted as time goes by. The rate of change in a person is ultimately more important than the amount of
change in an individual. Patients want to know about their disease. Can it be treated with surgery, chemotherapy or radiation therapy? They also wish to know when therapies are no longer effective so that they can take an active part in the decision-making process regarding how to live the life that they have left. There has been a shift away from length of life towards quality of life and an examination of the burdens and benefits of treatment options. "A shift toward a quality of life focus is occurring throughout medicine and is part of the patient-centered model of care. Using this approach, clinicians respond to issues of greatest importance to patients and their families" (Larson, & Tobin, 2000, p.1576). McCormick and Conley (1995) state, “Patients experience a reduction in both physical and psychological aspects of suffering when physicians use good communication skills, are sensitive to patients’ perspectives, and actively work to reduce barriers to mutual understanding” (p. 236).

The knowledge of the importance of therapeutic communication will enhance the health care professional’s ability to enter into dialogue regarding the use and or possible role of hydration for his/her patient. They will be able to present facts, and understand the importance of spending time and reviewing the patient’s history, and helping the individual to define the goals which are most important regarding his/her death. Armed with this knowledge, the health care professional will have already come to mutual decisions about the role of hydration with his/her patient long before a crisis occurs.
Ethical decision-making

There are several models for ethical decision-making available in the literature. The Latimer Ethical decision making model (Latimer, 1998; Downing & Wainwright, 2006) is easy to understand and helps delineate the ethical problem without ignoring important components. This model looks at the patient’s experience, illness, and the patient as a person. It then examines the patient/family, along with the health care team, which results in the formulation of goals of care consistent with the best interests of the patient. This leads to consideration of possible treatments, an examination of burdens and benefits that are consistent with goals already outlined, and whether or not determination of life prolongation is a goal. Depending on the outcome of this discussion, there may or may not be opportunity for renegotiation of goals of care. This model is fluid, holistic, and incorporates the patient’s wishes and symptoms at the outset. In cases where the patient is unable to participate in the decision making process, a person may have a signed ‘Do Not Resuscitate (DNR) form’ or may have conferred medical decision-making to another person. Legally in BC, a provincial DNR form must be signed in order for no resuscitation to take place when an ambulance is called. At PGRH, patients are also asked to sign a ‘Level of Interventions form’. This is not a provincial form; however, it is a document whereby the patient and/or family member can decide upon how much treatment they would like to receive in case of say, a fractured hip. In the palliative care patient with a diagnosis of pneumonia, they could determine whether or not to receive treatment with antibiotics. In collaboration with the patient, family, and health care team, the goals of care are formulated. This allows for congruence of opinions which does not always happen in end of life care.
Incorporating ethics into end of life care is not so much about what to do, but how to proceed, utilizing the principles of compassion, respect, integrity, and fairness. This will then guide care and practice for the patient (Downing & Wainwright, 2006). Hayes (2004) discusses that goals of care must be established before burdens or benefits of a potential treatment can be weighed accordingly. This strongly supports concepts outlined in Latimer's model.

**Ethics and palliative care**

The ethical principles of beneficence, nonmaleficence, truth, justice and autonomy are integral to the practice of palliative care (Latimer, 1998; Downing & Wainwright, 2006; Doyle, Hanks, Cherny & Calman, 2004). Beneficence is often viewed as the ‘doing of good’ to or for an individual. Nonmaleficence is widely defined as the principle of not doing harm. Autonomy is often described as self-determination, or the moral right to choose and follow one’s own plan of life and action. This principle is strongly supported in Western culture perhaps more so than other ethical principles. Other cultures believe that autonomy is ‘transferred’ or rooted in a substitute decision-maker for cultural or religious reasons (Downing & Wainwright, 2006). Autonomy not only rests with the patient, but also members of the health care team who are caring for that particular individual. In order for a patient to exercise their autonomy, they need to have the most complete and accurate information in order to make the best decision for themselves (Looney, 2000). Justice is viewed as equity in not only urgent treatment, but treatment in an office setting. The principle of justice might apply on a larger scale, for example at the health authority level, and the treatment of palliative care individuals within a community program (Downing & Wainwright, 2006).
The literature reviewed for this project suggests that there are many ethical principles for consideration when working and caring for those who are receiving palliative care. The Canadian Nurses Association (CNA, 2008) code of ethics outlines more than just the principles mentioned above. They include: “Providing safe, compassionate, competent and ethical care, promoting health and well-being, promoting and respecting informed decision making, preserving dignity, maintaining privacy and confidentiality, promoting justice and being accountable” (p.3). All of these principles have the ability to guide care for those who are deemed palliative or receiving end of life care. Nurses then have a guide to follow in the provision of ethical care. Ersek (2003) in her review paper summarizes all of these principles by stating, “Nurses also should provide guidance to patients and families in decision-making that includes evaluation of the patient’s current condition and prognosis, accurate clinical information, a clear and complete discussion of treatment options, and consideration of the patient’s and family’s values and beliefs about dying, death, family roles, and nurturing as well as their goals for care” (p.227).

Downing and Wainwright (2006) also mention several ideas or principles that influence ethics in end of life care. The principle of double effect is when an action results in two effects, one that is intended, and one that is not. Proportionality, utilitarianism, competence, non-abandonment, informed consent, truth telling, confidentiality, paternalism, advance directives, discrimination, clinical judgment, futility, withholding/withdrawing treatment, and refusal of treatment are all ethical principles discussed by Downing and Wainwright (2006) in relation to end of life care. Latimer (1998) documents the following as requirements for ethical care: careful physical assessment and diagnosis, communication, setting goals of care, relief of pain and suffering, ongoing attentive care, interdisciplinary approach,
practicing in a cultural context, symptom control, use of treatments and procedures, cessation and non-initiation of treatment. The underlying premise of all ethical care is that patients who are dying are entitled to a high standard of professional care that recognizes the patient's worth as a human being and their individual uniqueness (Latimer, 1998). Byock, (2004) expands upon these basic principles by discussing the ethic of loving care. He writes that there should be balance between caring, as well as other ethical principles.

Futility in palliative care

There is also the matter, in end of life care, of the determination of futile versus palliative care (Hayes, 2004). Kasman (2004) indicates that, "... in order for futility to be useful in clinical decisions, various involved parties need to negotiate and agree upon specific goals for treatment" (p. 1054). Downing and Wainwright (2006), and Latimer (1998) mention that goals of treatment need to be outlined when discussing ethical care. Kasman (2004) notes there are several things physicians need to be aware of regarding futility. Physicians are not obligated to provide treatments that they believe are ineffective or harmful to patients. A physician needs to weigh the benefits and burdens of a potential treatment then balance it against the goals of treatment for an individual. Physicians should be cautioned not to say 'no' when a patient requests a treatment they believe to be futile; instead, they should engage in dialogue with the individual. This insures the individual is fully informed, and has the ability to exercise his/her autonomy regarding decision-making. It is not helpful for physicians to state that medical care is futile, rather, the physician should discuss such things as 'aggressive treatment' and/or treatments that provide 'comfort' (Kasman, 2004).
It is clear that the physician or nurse practitioner plays a crucial role in ensuring that accurate information is being conveyed at all times and options are presented to the individual in terms that they can understand. The result is then potential for increased dialogue with the patient and determination of outcomes of care that will never be perceived as being futile. In addition to the concept of futility, informed consent, "...goes beyond the question of whether consent was given for a treatment or intervention. Rather it focuses on the content and process of consent" (Downing & Wainwright, 2006, p.50). The physician needs to ensure that the information provided is understandable to the patient, is unbiased, and should include the physician's recommendations. Agreement by the patient must be free and without coercion (Downing & Wainwright, 2006).

**Ethics and artificial hydration**

Looney (2000) discusses that the principle of nonmaleficence is to do no harm. Frequently the terms ‘ordinary’ and ‘extraordinary’ are used to provide the context for discussing end of life care and are linked to discussions of nonmaleficence. Ordinary in this case refers to that which offers reasonable hope or benefit and may be used without creating a significant burden on the patient. Extraordinary refers to the utilization of treatment options that cannot be provided without significant burden, or a treatment option that offers little hope of benefit. Ersek (2003) and Allari (2004) specifically address the issues of food and fluids, artificial hydration and nutrition in this regard. Ersek (2003) states, "Patients and families must consider all options given their values and beliefs, the patient’s prognosis, and clinician recommendations. Decisions regarding ANH [artificial nutrition and hydration] are often made in highly charged situations in which the decision-makers are concomitantly trying to cope with grief and loss" (p. 22).
This suggests that, in many cases, adequate communication may not have taken place, and/or changes may have occurred rapidly to an individual resulting in further discussion regarding treatment options. The principles of providing information, communicating treatment options in light of prognosis, and consideration of the patient’s values, cultural, and spiritual beliefs are all relevant. Allari (2004) notes that conflicts arise when the patient is unable or unwilling to eat and family members urge them to eat, which shifts the focus away from the tasks of dying such as letting go, reconciliation and spiritual growth. Family members often use the word ‘starve’ in relation to their loved one at the end of life, and this concept is often used as an argument to health care providers. There is a difference between starving and hunger. In starvation the person wishes to eat but does not have food, whereas in hunger the person does have food and can eat. The situation for those who are dying is that there is food available but the individual may have little or no appetite, taste changes, nausea or vomiting, or simply is not hungry. As a person approaches death, their desire for food and fluids decreases (Allari, 2004; Downing & Wainwright, 2006; Doyle, Hanks, Cherny & Calman, 2004; Ganzini, 2006). Neither artificial hydration nor nutrition is similar to eating or drinking, “There is no taste, no pleasure; there is nothing social or nourishing, furthermore, the dying patient is seldom hungry” (Allari, 2004, p.90).

A study recently published (Oh et al., 2007) speaks to the importance of the cultural perspective. This Korean retrospective study looked at the use of artificial hydration to patients with terminal cancer. They discovered that over 75% of patients received artificial hydration via intravenous route during their last days of life. They concluded that Korean physicians consider artificial hydration a minimum standard of care, believe it is helpful for symptom management, it may not affect patient suffering, and withholding of intravenous
fluids may shorten the patient’s life to some degree and is ethically unacceptable (Oh et al., 2007). This is in direct contrast to studies done in Europe and North America. Therefore, what seems ethical to one group of practitioner’s may not seem ethical to another group and there is certainly room for further research on both sides of the discussion and amongst different ethnic populations. Keeping an ethical perspective regarding this area is very important for the health care professional.

Published reports indicated that normal biochemistry serum values have been documented in individuals that are dying, thus discounting the belief that all palliative care patients are clinically dehydrated prior to death (Ellershaw, Sutcliffe & Saunders, 1995; Morita, Tei, Tsunoda, Inoue, & Chihara, 2001). Studies have shown that thirst is common in the days and hours leading to death and can be assuaged with oral care or sips of fluid (Dalal & Bruera, 2004; Morita et al., 2001). Provision of food and fluid at end of life is a complex and challenging dilemma. Morally and ethically, the literature indicates that provision of food and fluid is a basic human right, which expresses caring and tangible evidence of proper nursing care (van der Riet, Good, Higgins, & Sneesby, 2008). Therefore withholding food and fluid from an individual who is dying, or refusing it, is extremely hard for family members and loved ones to accept. This event often signals the onset of the actual dying process. It’s presentation can be a difficult dilemma for the health care practitioner as he/she balances clinical evidence, research, best practices, and ethical concepts in the caring of the individual (Casarett, Kapo & Caplan, 2005; Mathes, 2001). Schmidlin (2008) discusses the angst of a physician’s son who requests an intravenous line for his dying father’s last hours; the son stated to the nurse how hard it was to be present and not ‘do’ something. The point here for health care providers is to reassure family members that by being present they are
doing something. If the burdens and benefits of artificial hydration are made clear to an individual who is in the last days of life, does their right to autonomy supersede clinical decision-making? Decreased hydration prior to death can reduce clinical symptoms of: vomiting, respiratory secretions, urinary output, edema and ascites, while inducing the by-products of dehydration which act as natural anesthetics causing decreased levels of consciousness and perhaps decreased suffering (Dalal & Bruera, 2004; Zerwekh, 1983).

Conversely, the provision of fluid prior to death provides: a basic human need, prevents confusion, agitation, and neuromuscular irritability, and allows providers time to continue their efforts to find ways to improve comfort and quality of life (Bridge, Miller, Cameron & Goldman, 2005; Dalal & Bruera, 2004).

A retrospective chart review was performed in Edmonton looking at the management of hydration at end of life (Lanuke, Fainsinger, & deMoissac, 2004). A comparison between hospice care, palliative in patient care, and acute care were examined in terms of amount of hydration administered, as well as other variables. The authors found that hydration is managed differently depending on the care setting. Hospice care generally did not include rehydration of patients, whereas, hydration was administered in acute care and inpatient palliative care settings (Lanuke, Fainsinger, & deMoissac, 2004).

A randomized controlled trial (RCT), prospective study, palliative literature review, a review, a systematic review, and clinical practice guidelines were retrieved in order to look at artificial hydration in palliative patients receiving end of life care. Bruera et al. (2005) conducted a RCT of administration of parenteral hydration in terminally ill cancer patients (n = 51). This study was conducted in different countries and patients were randomly assigned to the control or placebo group. The significance of this study was that
improvement in symptoms of myoclonus (p=.035) and sedation (p=.005) after receiving hydration was demonstrated. The study sample was very small suggesting more work to be done with this population. Dehydration was a clinical indicator for inclusion of study participants. Dry mouth and thirst were not included as factors because the association between these symptoms and hydration of cancer patients is limited (Bruera et al., 2005).

In a different study, Ellershaw, Sutcliffe and Saunders (1995) looked at the effect of respiratory tract secretions and patient symptoms of dry mouth and thirst. Serum studies showed that half of the patients (n=82) had normal serum osmolality with serum sodium and potassium and blood urea nitrogen (BUN) being in the normal range. A high number of study participants with normal blood work (except low albumin and total protein) indicated that they experienced dry mouth and felt thirst. Hydration was not offered as this study was conducted in an inpatient hospice setting. The following were identified as difficulties within the study: the validity of biochemical dehydration definition was not clear, it had a small study population, there was a low response rate to the question regarding ‘thirst and dry mouth’ and the statistical power was not addressed (Good, Cavenagh, Mather & Ravenscroft, 2008).

An interesting study by Morita, Tei, Tsunoda, Inoue and Chihara (2001) looked at serum samples for clinical dehydration, and atrial natriuretic peptide (ANP) suspecting an association between high levels of ANP and thirst. They confirmed that: “…the traditional view that dehydration defined by BUN, creatinine, sodium and osmolality is not correlated with the thirst experienced by terminally ill cancer patients” (p.183). When using ANP as an indicator for dehydration, statistical analysis (p=.014) showed that it could determine dehydration as a clinical cause of severe thirst in study patients. There has been no
documented correlation between sensation of thirst and the administration of artificial hydration (Morita et al., 2001). Furthermore, thirst seems to be independent of a diagnosis of dehydration (Ellershaw, Sutcliffe, & Saunders, 1995; Morita et al., 2001).

Plonk and Arnold (2005) present information related to care for those in the last weeks of life. They discussed many end of life symptoms including pain and dyspnea, and provided some insight into how artificial hydration might be administered. The section on hydration emphasized that most dying patients lose their appetite and also lose weight resulting in: “a ketosis that contributes to a sense of well-being and diminished discomfort” (p.1045). This work highlights the ongoing debate regarding hydration and dying patients in terms of the clinical, legal, ethical and religious opinions (Plonk & Arnold, 2005). The reader has to be discerning about the information because patients with gastrointestinal or esophageal carcinomas can do very well for a time, with artificial nutrition and hydration (Downing & Wainwright, 2006). For those who are not imminently dying, but suffering from neurotoxicity, fluid can be helpful (Bruera et al., 2005). Some experts argue that parenteral hydration prevents and treats some cases of terminal delirium. Bruera, et al. (2005) showed that hydration could improve such symptoms as myoclonus and sedation. However, there is no correlation between dehydration and symptoms, and rehydration may not improve patient comfort. Plonk and Arnold (2005) conclude that, “While there is little objective evidence of harm, the bulk of current evidence and expert opinion supports the conclusion that parenteral hydration is likely not beneficial in the actively dying patient” (p.1046).

Dalal and Bruera (2004) provide information regarding physical aspects and other factors that can result in dehydration in the cancer patient. They make an interesting point that physical examination of the patient alone has a low sensitivity and specificity for
determining fluid status. The signs of dehydration in a patient with cancer are less reliable compared to a normal population (Dalal & Bruera, 2004). They also note that two most distressing symptoms are, sensation of thirst and dry mouth, however, these symptoms can occur as a result of thrush, use of certain medications, mouth breathing, and radiation (Dalal & Bruera, 2004). Their arguments for and against hydration are documented in a chart form that is easy to read (see Appendix B). The underlying premise surrounding the delivery of artificial hydration is to ensure that the patient’s and family’s goals of care are addressed (Dalal & Bruera, 2004). Communication is essential in reviewing the benefits and burdens of care with the patient and family and the ethical issues that arise as a patient’s condition deteriorates. Dalal & Bruera (2004) conclude, “To continue with a treatment that was appropriate at first but no longer has clinical meaning makes little clinical or ethical sense. Patients, families, friends and caregivers should know that hydration can be ethically withheld and withdrawn” (p.473).

A systematic review by Good, Cavenagh, Mather and Ravenscroft (2008) examined 5 studies regarding the use of artificial hydration in palliative care patients. Two of the studies were RCTs (Bruera et al., 2005; Cerchietti, Navigante, Sauri, & Palazzo, 2000); the other studies were prospective control trials (Morita, Tei, Tsunoda, Inoue & Chihara, 2005; Waller, Hershkowitz, & Adunsky, 1994; Viola, 1997). The review was to determine the effect of medically-assisted hydration on quality and length of life. Some of the studies did not address these specific outcomes and looked at other specifics such as: thirst, respiratory secretions, sedation level, and myoclonus. Good, Cavenagh, Mather and Ravenscroft (2008) concluded that there are insufficient quality studies to make any recommendations for practice regarding the use of artificial hydration in palliative care patients stating, “Clinicians
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will need to make a decision based on the perceived benefits and harms of medically assisted hydration in individual patient circumstances, without the benefit of high quality evidence to guide them” (p.6).

Morita, Bito, Koyama, Uchitomi and Adachi (2007) developed a set of National Guidelines for the use of artificial hydration in palliative care. This is a well-researched document, establishing consensus among a large panel of experts from different fields. One disadvantage is that these guidelines were specifically established for a particular country. Differences between cultures and primary etiology of cancers may in fact render the guidelines as perhaps not suitable. However, this writer’s examination of these guidelines generally found them more specific regarding artificial hydration compared to other North American and European guidelines (Bridge, Miller, Cameron & Goldman, 2005; CHPCA, 2002b; NHA, 2008).

Summary of key findings

The literature search reveals a number of important findings. The debate regarding artificial hydration and end of life care has been ongoing for many years. There is enough information to state that administering hydration in individuals who are dying is not indicated. However, for those who are not imminently dying and are experiencing dehydration and/or oversedation and/or myoclonus, a trial of fluid could be initiated. Research indicates that fluid can be given in a number of different ways, and for those whose health and physical being is fragile, hypodermoclysis could be considered (Dalal, Del Fabbro, & Bruera, 2009; Dunphy, Finlay, Rathbone, Gilbert & Hicks, 1995; Steiner, & Bruera, 1998). The benefits and burdens of this treatment must be clearly understood by the individual and family members. The practitioner needs to ensure that the goals of care are
clear, consistent and coherent among team members. The ethical implications and the physical setting of the individual will contribute to the decision-making. Chapter 3 includes a discussion of artificial hydration for end of life care, implications for nurse practitioner practice, as well as providing the reader with recommendations for next steps in developing best practice guidelines related to this issue.
CHAPTER 3

*Implications for Nurse Practitioner Practice*

In reviewing the background and context regarding artificial hydration in hospice palliative care/end of life care, there are three main conclusions that should guide clinical practice. First, the nurse practitioner (NP) or health care provider must be able to recognize functional decline in individual patients as a possible precursor to death within 6 months to one year. Second, the nurse practitioner must be able to diagnose ‘dying’. The ability to diagnose a patient as dying allows the patient and the family to realize what is happening, and directs care by health care professionals towards managing comfort and the psychosocial aspects associated with dying. Finally, the nurse practitioner must take a lead role in end of life communication in order to prepare patients and family members for death and dying and, consequently, provide information regarding artificial hydration. Implications for research and education are beyond the scope of this project, thus are not discussed here.

*Illness trajectory and implications for clinical practice*

The literature indicates that only 10% of the population experiences sudden death (Ellershaw & Ward, 2003). The rest of the population tends to have chronic disease and lives with disease until death. What does this mean for clinical practice? Nurse practitioners need to be aware that the majority of patients will have chronic disease and at some point will require hospice palliative/end of life care. It is a realistic expectation that a nurse practitioner (family) providing primary care will have to address death and dying with their patients (CRNBC, 2009). It is important to be aware of the options available to individuals in the community, and the supports and benefits of being registered with hospice palliative care. It is also important to engage the individual and family in advance care planning. In the best
practice guidelines for care of the frail elderly from BC, the importance of advance care planning is included (BC Ministry of Health, 2008). The nurse practitioner utilizes knowledge of pathophysiology of disease progression and illness trajectory in order to help manage physical symptoms. Nurse practitioners are in a unique position to spend more time with the patient and family than physician providers due to a financial reimbursement system which is not ‘fee-for-service’. There is freedom to do home visits and liaise with individuals in the system. For example, these interactions may include home care nurses, palliative care consultant, physician colleagues, and laboratory services. The recognition of functional decline and advance care planning may help to prevent urgent or emergent visits to the emergency room for symptom management. Plonk and Arnold, (2005) argue that addressing goals of care with patients prior to the terminal phase is good clinical, ethical, and compassionate care. It is far better to discuss options with patients and families prior to sudden changes in physical decline and crisis events. Discussion of end of life issues, and provision for non abandonment of care is ideally suited to the role of the nurse practitioner (Quaglietti, Blum, & Ellis, 2004).

Diagnosing “dying”

The nurse practitioner needs to be able to make a diagnosis of “dying”. For patients who are actively dying there is then the importance of dealing with symptom management, comfort, and possibly discussion of the issue of fluids and hydration. This is not easy and there is often reluctance on the part of health care professionals to make a diagnosis of dying if there is a possibility of hope for improvement. However, it is better for a health care practitioner to be honest and open with the patient, especially in the event of no definitive diagnosis. Some health care professionals would argue that it is unethical to make a
diagnosis of dying if a patient does not have a diagnosis. However, it is unethical to withhold treatment and knowledge of symptom management from a patient if they require it. A case in point: A 60 year old female patient was admitted to hospice house from PGRH with dyspnea and inability of the acute care setting to offer any other curative therapy for this individual. This writer recalls phoning the family physician to ask for medication orders for extreme dyspnea. The family physician kept stating on the phone, “she does not have cancer anymore”. The issue for that family physician was that the patient no longer had cancer, therefore did not require usual palliative medications for symptom management. This writer’s point was that the patient was experiencing severe dyspnea and required management for dyspnea regardless of other underlying pathology.

Ideally a clear diagnosis is the gold standard for each patient; in reality this is not always the case. However, if a patient is dying, care and symptom management can still proceed without diagnosis. The diagnosis then is that the patient is dying. Ellershaw and Ward (2003) state,

The most important element in diagnosing dying is that the members of the multi-professional team caring for the patient agree that the patient is likely to die. If the team members are in disagreement then mixed messages together with opposed goals of care can lead to poor patient management and confused communication...Once dying has been diagnosed, the team can then refocus care appropriately for the patient (p. 30).
Communication

Communication is the cornerstone of every interaction between nurse practitioner and the patient and family. The nurse practitioner needs to be aware of the importance and impact of the anorexia-cachexia syndrome (ACS) on individuals and families. Many patients will have been focused on food and fluids for many months as a result of ACS. The patient may have spent time with a dietician and worked very hard in order to ensure the best possible intake of food and fluids in order to ‘beat’ cancer. Patients may continue with medications in order to battle ongoing nausea, vomiting, and/or to improve appetite. This needs to be remembered by the nurse practitioner, because when a patient’s intake decreases, or stops, it may be exceedingly difficult for the patient and family to understand non-provision of artificial hydration at end of life.

Artificial Hydration Evidence and Recommendations

With respect to artificial hydration at the end of life, the nurse practitioner must keep in mind the following when communicating with the patient and family:

- Evidence states that there is a natural and expected gradual decline in food and fluid intake as the individual approaches death (Cimino, 2003; Dalal & Bruera, 2004; Plonk & Arnold, 2005; van der Riet, Good, Higgins, & Sneesby, 2008).

- There is no obvious evidence demonstrating that the sensation of thirst can be relieved by the provision of artificial hydration in end of life care (Morita, Tei, Tsunoda, Inoue, & Chihara, S. (2001)).

- If hydration is considered, hypodermoclysis may be an easier route for some patients/families, an appropriate volume (less than 1000mL/ day) and discontinuation
of treatment if no benefit are all important factors (Dalal, Del Fabbro & Bruera, 2009; Lanuke & Fainsinger, 2003);

- Determine individual goals of care with the patient, family, and multidisciplinary team and deliver care based on these goals (Burge, 1996; Dalal & Bruera, 2004, Dalal, Del Fabbro & Bruera, 2009; Lang & Quill, 2004; Morita et al., 2007; Suter, Rogers, & Strack, 2008; van der Riet et al., 2008).

For patients who are not actively dying, there is time to discuss beliefs and values about fluid and hydration, as well as review physical signs and symptoms. It is important to also discuss with the patient and family options and goals for care, location of death, caregiver availability, and choices and decisions that the family or patient wishes to pursue. The nurse practitioner can ensure that goals of care are followed, with the knowledge that changes may occur depending on progression of symptoms and ability of family members to cope.

Minimally, the nurse practitioner needs to be fully knowledgeable about the benefits/burdens of hydration therapy, different modes available, amount and type of hydration to be utilized, location of the patient and the ability to communicate this information to the patient and family. This communication will reflect therapeutic skills of the nurse practitioner, use of empathy, compassion, ethical principles, and recognition of cultural, ethnic and spiritual beliefs as well as the work of dying.

The ability of the nurse practitioner to communicate with patients and families during end of life care will enhance care that is given. Plonk and Arnold, (2005) suggest, “Excellent communication is essential during the dying process; bereaving families identified improved communication around the time of death as the single most important means of improving
end-of-life care. One quarter of families across care locations expressed concerns specifically with physician communication during terminal care. Physician empathy as death approached has been shown to reduce caregiver depression and psychosocial burden”.

(p.1049).

Recommendations for Nurse Practitioners

In order to ensure that nurse practitioners are able to have a positive impact on end of life decisions including initiation of artificial hydration, nurse practitioners must have:

- The ability to admit patients to hospice house for palliative care and continuity of care;
- The ability to sign death certificates for patients with known palliative diagnoses and chronic diseases;
- The ability to prescribe narcotics and benzodiazepines for end of life care;
- An ability to work collaboratively with other health care professionals providing care for patients who are dying;
- The ability to admit patients to an acute care facility for end of life care and;
- Support to attend continuing education events around hospice palliative care.

Conclusion

To answer the research question, yes, this author believes that there is a place for the use of artificial hydration in end of life care. However, it needs to be on an individual basis after the goals of care for that person have been agreed upon and delineated, and if adverse effects ensue, then hydration should be stopped. The role of artificial hydration in end of life care is complex and will necessitate the entire breadth of skills of the nurse practitioner in order to effectively communicate with patients and family members regarding this subject.
Recognition of hospice palliative care, illness trajectory, functional decline, therapeutic communication, ethical principles and knowledge of the debate regarding artificial hydration are indispensible. Therapeutic communication, use of a multidisciplinary team and the development of an individual’s plan of care are essential in order to provide the best possible end of life care for patients.
Artificial hydration at the end of life

References


Bridge, D., Miller, C., Cameron, D., & Goldman, H. (2005). Forum: The role of nutrition and hydration when sedation is used in palliative patients. *European Association for Palliative Care*. Retrieved from:

http://www.eapcnet.org/forum/default.asp?category=The%20Role%20of%20Nutrition%20and%20Hydration


Artificial hydration at the end of life


Artificial hydration at the end of life


Appendix A - The Work of Dying

A working set of...

Developmental Landmarks and Taskwork for the End of Life

<table>
<thead>
<tr>
<th>Landmarks</th>
<th>Taskwork</th>
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<tr>
<td>Sense of completion with worldly affairs</td>
<td>Transfer of fiscal, legal and formal social responsibilities</td>
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| Sense of completion in relationships with community | Closure of multiple social relationships (employment, commerce, organizational, congregational)  
Components include: expressions of regret, expressions of forgiveness, acceptance of gratitude and appreciation  
Leave taking; the saying of goodbye |
| Sense of meaning about one's individual life | Life review  
The telling of "one's stories"  
Transmission of knowledge and wisdom |
| Experienced love of self | Self-acknowledgment  
Self-forgiveness |
| Experienced love of others | Acceptance of worthiness |
| Sense of completion in relationships with family and friends | Reconciliation, fullness of communication and closure in each of one's important relationships.  
Component tasks include: expressions of regret, expressions of forgiveness and acceptance, expressions of gratitude and appreciation, acceptance of gratitude and appreciation, expressions of affection  
Leave-taking; the saying of goodbye |
| Acceptance of the finality of life - of one's existence as an individual | Acknowledgment of the totality of personal loss represented by one's dying and experience of personal pain of existential loss  
Expression of the depth of personal tragedy that dying represents  
Decathexis (emotional withdrawal) from worldly affairs and cathexis (emotional connection) with an enduring construct  
Acceptance of dependency |
| Sense of a new self (personhood) beyond personal loss | Developing self-awareness in the present |
| Sense of meaning about life in general | Achieving a sense of awe |
| Achieving a sense of awe | Recognition of a transcendent realm |
| Recognition of a transcendent realm | Developing/achieving a sense of comfort with chaos |
| Surrender to the transcendent, to the unknown - "letting go" | In pursuit of this landmark, the doer and "taskwork" are one. Here, little remains of the ego except the volition to surrender. |

Reference:

Table 1
The Hydration Debate

**Arguments for hydration**
- Provides a basic human need
- Provides comfort and prevents uncomfortable symptoms: confusion, agitation, and neuromuscular irritability
- Prevents complications (eg, neurotoxicity with high-dose narcotics)
- Relieves thirst, recognized as a sign of fluid needs
- Does not prolong life to any meaningful degree
- Allows providers to continue their efforts to find ways to improve comfort and life quality, despite the perception of a poor quality of life
- Provides minimum standards of care; not doing so would break a bond with the patient
- May set a precedent to withhold therapies from other patients who are compromised

**Arguments against hydration**
- Interferes with acceptance of the terminal condition
- Intravenous therapy is painful and intrusive
- Prolongs suffering and the dying process
- Unnecessary since unconscious patients do not experience uncomfortable symptoms, such as pain or thirst
- Less urine output means less need for bed pan, urinal, commode, or catheter
- Less fluid in the GI tract and less vomiting
- Less pulmonary secretions and less cough, choking, and congestion
- Minimizes edema and ascites
- Ketones and other metabolic by-products in dehydration act as natural anesthetics for the central nervous system, causing decreased levels of consciousness and decreased suffering

Reference: