DEHYDRATION SYMPTOMS OF PALLIATIVE CARE CANCER PATIENTS

Frederick Burge, M.D.

Department of Epidemiology and Biostatistics

A Thesis submitted in Partial Fulfillment of the Requirement of Master of Science Degree

McGill University, Montreal

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Abstract

Controversy exists among clinicians and caregivers as to whether reduced fluid intake contributes to the suffering of those dying of advanced cancer. This study explored the distribution of proposed "dehydration state" symptoms among inpatient palliative care cancer patients. Fifty-two subjects responded to a seven item self-report questionnaire using visual analogue scales. Associations were determined between the symptom self-reports and the possible predictor variables fluid intake, serum sodium, urea and osmolality. Confounding variables considered were age, oral disease and mouth care regime. Mean symptom ratings (range 0-100 mm) were: thirst 53.8, dry mouth 60.0, bad taste 46.6, nausea 24.0, pleasure to drink 61.6, fatigue 61.8, and pain 33.5. No significant association was determined between symptom ratings and the predictor or confounding variables. Although the symptoms appear to be rated moderately severe, there was no demonstrable association between severity and fluid intake, the key concern of clinicians and families.

Abrégé

Il n'est pas clair pour les cliniciens ou les personnes soignantes si une consommation réduite de liquide contribue à la souffrance des mourants par cancer. Dans cette étude, nous décrivons les symptômes associés à la déshydratation chez des patients dans une unité de soins palliatifs. Dans ce but, cinquante-deux patients ont répondu à sept questions presentées sous forme d'échelle analogique visuelle de 100mm. Nous avons évalué l'association des symptômes avec les variables predictives suivantes: la consommation de liquide, le sodium sérique, l'urée et l'osmolalité. Nous avons aussi évalué le rôle des variables potentiellement confondantes telles l'âge, l'hygiene buccale et les maladies de la bouche. Sur l'échelle de 0 à 100 mm, les patients ont donné à leurs symptômes les valeurs moyennes suivantes: soif 53.8, sécheresse de la bouche 60.0, goût désagréable 46.6, nausée 24.0, plaisir associé au boire 61.6, fatigue 61.8, et douleur 33.5. Nous n'avons decele aucune association significative entre les valeurs accordees aux symptômes et les variables prédictives ou confondantes. Bien que les valeurs données aux symptômes apparaissent moderement sévères, il n'y avait pas d'association entre la severite et la quantité de liquide prise; ce point est d'interêt majeur pour les cliniciens et les personnes soignantes.

Acknowledgements

Special thanks to:

- Dr. P. Tousignant, Dr. D. Lamping and Dr. L. Joseph
- The Palliative Care Service of the Royal Victoria Hospital
- The Montreal Convalescent Hospital Centre
- Health and Welfare Canada for a National Health Fellowship, National Health Research and Development Program
- Bernice King and John O'Connor
- The 52 subjects, who have now all died.

1.0 Introduction

Cancer represents the second most common cause of death among Canadians. In 1988 almost one-third of the total national mortality, 50,000 Canadian deaths, was due to cancer (Canadian Cancer Society, 1988). Several factors have led to changes in the way advanced cancer patients are cared for today. First, many more people die of cancer today than did thirty years ago. Wigle, Mao, Semenciw and Morrison (1986) report that between 1951 and 1983 there was a "lack of substantial improvement in (mortality) rates for the most frequent types of cancer". Bailar and Smith (1986), in a review of American cancer mortality statistics, confirm this trend in their report of increases in the number of deaths between 1950 and 1982. Their report for cancer patients notes increases, not only in the crude cancer-related mortality rate, but also in the age-adjusted mortality rate.

Katz, Zdeb and Therriault (1979), and Flynn and Stewart (1979) cite a second factor concerning cancer which has changed in recent decades. This is the shift to dying in institutions, including hospitals and nursing homes. As a result, clinicians are faced with an ever increasing need to care for those for whom cure is not possible. These same clinicians must confront issues in terminal care which formerly might have been dealt with in the home, but which now are present in an institutional setting. Decision-making situations in this milieu are easily influenced by easy access to technology and intervention. Such situations may include the appropriate use of chemotherapy, surgery and

radiotherapy; decisions not to resuscitate; and cessation of therapies such as ventilators, antibiotics, chemotherapy and nutritional supplementation. The management of dehydration in terminally ill patients is one of the most challenging of these issues because of the complex physical, moral, ethical, legal and cultural factors which influence the decision-making process.

Lacking clear definition, terminal dehydration may be understood as the clinical state of those dying patients who no longer are able to consume "adequate" fluid volumes usually associated with maintenance hydration requirements. This "dehydration state" has been described by some (Ramsey,1978; Siegler and Weisbard, 1986; Siegler and Weisbard, 1989; Micetich, Steinecker and Thomasma,1983) as being associated with intolerable suffering which should be relieved. The suffering is believed to include thirst, dry mouth, fatigue, lethargy, nausea, vomiting, confusion, muscle cramps and perhaps even the hastening of death.

By contrast, others (Zerwekh, 1983; Printz, 1988; Billings, 1985; Twycross and Lack, 1986; Campbell-Taylor and Fisher, 1987; and Brown and Chekryn, 1989), in examining the problem of dehydration-related suffering in dying patients, have emphasized the role of inappropriate medical management as a major contributor to symptom distress rather than the state of dehydration itself. They argue that the adverse effects of intravenous fluid therapy may include repetitive venipuncture, decreased mobility, possible congestive heart failure, excess respiratory secretions, edema and skin breakdown (Zerwekh, 1983).

Campbell-Taylor and Fisher (1987) describe how nasogastric tube feeding may involve patient inconvenience, discomfort and even aspiration of the nutritional supplement resulting in pneumonia. Furthermore, these authors state that dehydration-related symptoms may be controlled with compulsive mouth care.

The presence, therefore, of intravenous fluid lines and nasogastric tubes may only serve to focus the attention of all involved on issues of fluid and electrolyte balance and medical technology, rather than on integrating the reality facing them.

Factors contributing to this polarization of opinion concerning the management of terminal dehydration include: differences in knowledge base and experience in terminal care; the pressures of conditioning in the traditional biomedical health care model to focus on the pathophysiology of disease rather than on the quality of life of the patient; fear of litigation; differences in the perception of the ethical and legal issues; and a lack of sound data from well-designed clinical studies as aids to reasoned clinical decision-making.

The purpose of this study was to determine the extent of symptoms associated with dehydration in hospitalized terminally ill cancer patients.

The specific questions examined were:

1) What is the distribution and severity of "dehydration state" symptoms in those with advanced cancer?

2) What are the psychometric properties, specifically reliability, of the dehydration state symptom questionnaire?

3) Are these symptoms, as measured by questionnaire, associated with objective measures of dehydration?

This study did not examine the ethical, symbolic, moral or legal issues of the hydration decision process for these patients, their families or clinicians.

2.0 Literature Review

The literature pertaining to dehydration in dying patients was reviewed in four domains: (a) the clinical aspects of dehydration and the decision-making process regarding treatment; (b) the objective measures of dehydration; (c) the subjective measures of dehydration symptoms; and, finally, (d) the possible confounding variables in the relationship between dehydration and symptoms that must be considered in order to enhance the strength of the data analyses.

2.1 Dying and Dehydration

To date there have been no studies which have quantified the symptoms of dehydration in dying cancer patients. Descriptive works by several authors who work principally with dying cancer patients in a palliative care setting present the most detailed examination of the clinical issue. Billings (1985), Zerwekh (1983) and Printz (1988) report the following symptoms have been associated with dehydration in these patients: thirst, dry mouth, lethargy, nausea, vomiting, confusion and coma. Standard medical texts report these same symptoms in their discussion of dehydration in general (Isselbacher, Adams, Braunwald, Petersdorf and Wilson, 1980; Dunagan and Ridner, 1989).

The degree to which patients experience these symptoms as significant contributors to their suffering remains uncertain. Twycross (1986) states that the prevalence of dry mouth is 40 per cent in patients admitted to Sir Michael Sobell House (a United

Kingdom Hospice). Elsewhere in his lists of symptoms experienced by almost 7000 admissions to the hospice, dry mouth and thirst are not mentioned (Twycross, 1986; Twycross, 1988). Norton and Lack (In Twycross and Ventafridda, 1979) report that "dry/sore mouth" occurs in 5 per cent of patients with advanced cancer. Wilkes (1974) does not include either symptom in the top ten symptoms complained of in a series of patients (296 individuals) admitted to a special unit for the dying. There are no other studies which report the incidence or prevalence of other symptoms as being ascribed to decreased fluid intake.

Printz (1988) suggests that dehydration may actually be analgesic. She proposes: "in the dehydrated patient perhaps the ketones produced during calorie deprivation cause a partial loss of sensation. It has been shown that some ketones have an anesthetic effect ..." She continues by saying that "in an advanced state of malnutrition and dehydration, pain relieving substances, possibly opioid peptides, are produced in increased quantity ... as studies with rats have shown that water deprivation causes an increase in dynorphyn - an extremely powerful opiate - in the hypothalamus."

These reports might, therefore, lead one to believe that this is not an important clinical issue. However, in a survey of physician attitudes by Micetich, Steinecker and Thomasma (1983) this was not the case. Ninety-six of 218 medical, surgical and pediatric house staff and attending physicians responded to the survey. Seventy-three per cent of respondents would have

initiated intravenous therapy for a patient with widespread incurable carcinoma in an irreversible coma. Furthermore, 84 per cent of these physicians would then maintain such therapy after three days of continuing coma and 40 per cent would use invasive means to secure the continued administration of intravenous fluids (i.e. central line or venous cutdown) solely for the purpose of maintaining hydration. In another tertiary care university hospital study, Burge, King and Willison (1988) found that 69 per cent of 106 patients who died of malignancy did so with an intravenous running. There was documentation regarding the indication for the intravenous in 59 per cent (63) of charts. The principal indication was to deliver non-analgesic medication and the second most common indication was for the provision of fluids for hydration. As approximately 72 per cent of cancer deaths occur in hospital (Katz, Zdeb and Therriault, 1979), it is clear that large numbers of patients die while undergoing parenteral therapy for the prevention of dehydration on the premise that it relieves suffering.

The specific symptoms that clinicians are attempting to relieve in the amelioration of suffering and the specific goals of intravenous therapy have not been studied; however, most authors quote the relief of dry mouth and thirst as the minimum goal (Ramsey, 1978; Zerwekh, 1983; Printz, 1988; Billings 1985; Brown and Chekryn, 1989). An anecdotal report by Oliver (1984) found that 10 of 22 patients who died of cancer without artificial hydration had elevated blood urea and essentially

normal electrolyte values ("or just outside the normal range"). He comments that "these seriously ill patients died peacefully, (within 48 hours) without the use of intravenous fluids ... using medical means to control their symptoms" (p.631). To date, there are no studies which have examined the association of these two symptoms with a measure of dehydration.

In summary, large numbers of terminally ill, hospitalized patients are receiving intravenous fluids for the relief of suffering when the extent of this suffering and that due to dehydration is not known.

2.2 Objective Measurement of Dehydration

Traditionally, several methods have been used to assess the hydration status of patients. These include: symptom reporting, physical signs, biochemical measures of serum and urine electrolytes and osmolality, renal function tests and total body water assessments. Symptom reporting, considered a subjective measure of dehydration, will be discussed in the next section.

Observation of skin tissue turgor, sunken eyes, acute weight loss and hypotension are all expected to be unreliable physical measures of the slowly evolving dehydration in dying cancer patients. This results from the fact that cachexia and malnutrition complicate the assessment of patients with advanced cancer. In an attempt to make objective the physical sign of dry mucous membranes, Gelenberg et al. (1985), in a study of antidepressant medications, used the change in weight of dental

rolls held in the mouth for two minutes as a direct indicator of moistness in the mouth and salivary flow. They concluded that this technique was able to demonstrate a difference between two groups expected to have different salivary flow. The technique has not been used in dehydration studies.

Kohan (in Dunagan and Ridner, 1989) describes minimum water requirements for fluid balance as approximately 1000 ml per day in order for the kidney to excrete 500 ml per day, the minimum to handle the daily osmotic load. Measuring either fluid intake or output would, therefore, provide one estimate of the adequacy of hydration status.

In a study of thirst following water deprivation, Rolls and Rolls (1980) found that when five healthy males were deprived of fluids for twenty-four hours there were significant elevations in serum osmolality and serum sodium concentrations. Mean predeprivation serum osmolality was 282.4 +/- 2.2 (mean +/- SEM) mosmol/kg and mean postdeprivation was 289.9 +/- 1.8 mosmol/kg. Serum sodium rose from a mean of 140.4 +/- 0.7 to 143.3 +/- 0.6 meq/l. The elevations returned to normal after rehydration. In another study (Phillips, Rolls, Ledingham et al., 1984), comparing young men (mean age 23 years) to older men (mean age 71), similar increases in serum osmolality and sodium were found. In the younger group sodium rose from 141.5 +/- 0.4 to 142.5 +/- 0.4 meq/l and serum osmolality from 287.7 +/- 1.8 to 290.4 +/- 1.1 mosmol/kg. In the older group, sodium rose more markedly from 140.2 +/- 0.4 to 143.2 +/- 0.5 meq/l and serum osmolality

from 288.4 +/- 1.3 to 296.3 +/- 1.2 mosm/kg. Engell et al (1987)also report the association between graded hypohydration and increasing serum osmolality. Baseline norms of serum osmolality were reported as 288 +/- 1 mOsm/kg (Thompson and Baylis, 1987) and 287 +/- 1 mOsm/kg (Thompson, Bland, Burd and Baylis, 1986). These studies suggest that these two laboratory measures (sodium and osmolality) are directly affected by dehydration in humans. The theory held is that as sodium and osmolality increase, so does the experience of thirst. From their data in 1986, Thompson et al. have calculated an osmotic threshold for thirst as being 281 mOsm/kg, the implication being that below this value, thirst is not experienced. There may not be, in fact, a fixed threshold but rather an individually set threshold. At the time of writing, there were no known studies which have measured serum electrolytes, urea, osmolality or other biochemical markers in dying patients other than the report by Oliver (1984) mentioned previously.

Methods which more accurately quantify the total body water of patients are generally much more invasive than the methods discussed so far. They include:

(1) Body densitometry methods (Behnke and Wilmore,1974) which require hydrostatic weighing of patients in a stainless steel tank. Mathematical formulae have been developed to provide total body water estimates.

(2) Tritiated water dilution techniques (Moore, Oleson, McMurrey, Parker, Ball and Boyden, 1963) require ingestion of a

specified dose of tritiated water and measurement of serum concentration of tracer at equilibrium, correcting for losses in urine.

(3) Bioelectric Impedance Analysis uses a small electrical current to measure the resistance to current flow in humans by surface electrodes (Lukaski, Johnson, Bolonchuk and Lykken, 1985). A regression equation estimates total body water from the impedance analysis. Unfortunately, a principal assumption underlying this technique is that total body water represents 74 per cent of lean body mass which is the derived quantity from the analysis. This assumption is not known to be valid in fluid deprived dying patients and, therefore, the technique cannot be assumed to be valid.

In summary, the latter methods are generally invasive and ethically unacceptable for research in dying patients. In addition, they are not methods most clinicians use in their routine clinical assessment of hydration status.

Physical signs are unfortunately unreliable in the face of cachexia and malignancy. This includes decreased skin turgor and sunken eyes.

This leaves, as objective measures, the assessment of fluid intake and output and the laboratory measures of sodium, urea and osmolality as the least invasive and most appropriate for this research study.

2.3 Subjective Measurement of Dehydration - Symptoms

Before discussion of the specific symptoms of dehydration, the concept of symptoms and the measurement of such subjective concepts must be outlined.

Rhodes and Watson (1987) describe in detail the concepts of symptoms, distress and symptom distress. They define symptoms as:

> "subjective phenomena regarded by the individual as an indication or characteristic of a condition departing from normal function, sensation, or appearance."(p.242)

> "Physical symptoms or sensations are private; therefore, it is difficult to measure objectively the causes responsible for symptom occurrence. In fact, since symptoms and/or feeling states are phenomena experienced by a person and not directly observable by another, symptoms only become known through the report of the person being assessed (eg, nausea, fatigue, pain)." (p.242)

It is now fairly well established that assessing symptom distress is best done through the use of self-report techniques (McCorkle, 1987; Huskisson, 1974 and McDowell and Newell, 1988). The only other alternative, "is the use of objective-based observations of distress by a trained interviewer or professional" (McCorkle, 1987,). She adds, "although, in general, correlations are reasonable, this comparison is problematic due to inherent differences in the way health is viewed and symptoms are perceived by the two groups" (p.248) (i.e. observers and patients).

In order to use statistical inference on subjective

assessments, some quantification of the descriptive statements must occur. Scaling techniques for descriptive statements originated in the early twentieth century (Freyd, 1923) and grew within social science research. In the 1970's the health sciences have intensively studied and used such techniques (McCorkle, 1987; Huskisson, 1974 and McDowell and Newell, 1988). Formats may vary from yes/no to a five point Likert scale, to the continuous visual analogue scale (VAS) (Fig. 1). Scales may be completed by a clinician, the patient or by a trained observer. The vast majority involve self-report by the patient.

The linear scales may have adjectives at intervals along the scale, at both ends of the scale, or both. These adjectives describe various gradations of a state the respondent is reporting. As an example, Huskisson (1974) has described a scale with the words "no pain" and "worst pain imaginable" as anchors at both ends of a 10-centimetre line (Fig. 2). This is a visual analogue scale (VAS). The VAS can have various forms, with and without adjectives or markings along the scale. It can be horizontally or vertically presented (Fig. 3). In the classic description of VAS development for the health sciences, Huskisson (1974) used the 10-centimetre VAS with anchor phrases at both ends (as in Fig. 2) but with no adjectives or gradations along the scale. Reliability studies of this VAS demonstrate high test-retest correlations of 0.994 at 5 minutes, 0.976 at 24 hours and repeatability correlations for vertical versus horizontal forms as 0.99 (Revill, 1976; Scott and Huskisson, 1976).

McCorkle (1987) reviewed several instruments which use the method of self-report for symptom distress. The Symptom Distress Scale is a thirteen item, Likert format self-report tool for use in practice and research in patients with chronic illness and cancer. Examples of the items include: nausea, appetite, insomnia, pain, bowel pattern, appearance, outlook, concentration, breathing, cough and fatigue. The phrases at the extremes of the fatigue item are, "I seldom feel tired or fatigued" and "Most of the time I feel exhausted". As with Huskisson's VAS for pain, the Symptom Distress Scale has been shown to be quite reliable (internal consistency coefficient alpha 0.79-0.89), and to demonstrate face, content, convergent and discriminant validity (McCorkle,1987). Thus, the measurement of symptom distress by self-reports has been shown to be reliable and valid.

Self-report methods have also been used to study the symptoms related to dehydration (Rolls and Rolls, 1980; Phillips et al., 1984; Wirth and Folstein, 1982; Engell et al., 1987). The VAS items have included thirst, dry mouth, the experience of unpleasant oral sensations, how pleasant it would be to drink and others. Typical of the descriptors is the question: " How thirsty do you feel now?". The VAS includes the anchors: "not at all thirsty" and "extremely thirsty".

Although the psychometric properties of these "dehydration state" VAS have not been extensively tested, several authors have presented initial evidence. Wirth and Folstein (1982) report

test-retest reliability for the thirst and dry mouth VAS (week to week over two months) at 0.79 ($p<0.001$) for hemodialysis patients. One item to item correlation for dry mouth and thirst was 0.99 suggesting that one of the items was adequate to measure the same content. Evidence for convergent validity was found in the correlation between patient and relative (e.g. a family member) reports of the VAS for thirst and dry mouth. This resulted in a correlation coefficient of 0.65 ($p<0.001$). The frequent use of corresponding adjectives (such as thirsty, dry mouth, tacky and sticky feeling tongue, etc) by the study subjects provide basic information that the same construct is being measured by the VAS (Rolls and Rolls, 1980 and Phillips et al., 1984).

The same VAS have been used in experimental studies of fluid deprivation in humans (Rolls and Rolls, 1980 and Phillips, 1984). Rolls and Rolls (1980) studied 5 healthy men, aged 24-33 years, during a 24-hour period of fluid restriction and then rapid oral rehydration. They found that the VAS was sensitive to changes in the hydration status of the individuals in that there were significant differences in the VAS scores corresponding to the hydration state of the subjects. Although presented only graphically in the text of the report, it appears that 24 hours of fluid deprivation caused an increase in the mean thirst score of approximately 5 centimeters. The other VAS changes were smaller: approximately 4 centimeters for pleasantness of drinking, 3 centimeters for dryness of mouth and 3 centimeters

for unpleasantness of taste in the mouth.

Phillips et al. (1984) studied the effects of similar fluid deprivation in 7 young (mean age 23 years) and 7 older (mean age 71 years) healthy men. Statistically significant increases in VAS scores for thirst and dry mouth occurred for the fluid deprived young men. There were increases also in the VAS scores for the older men for similar fluid deprivation, but these were not found to be statistically significant. With only 7 patients participating, however, the power to detect significant clinical differences was probably low.

Three studies provide baseline (euhydration) values for the symptom of thirst. The reported values on a 0-10 centimetre scale, include a VAS mean of 2.2 +/- 0.3cm (mean +/-SEM), (Thompson et al., 1986) and a mean of 0.9 +\- 0.2cm (Thompson and Baylis, 1987). A median value of 1 was reported by Engell et al. (1987) where a 0-9 categorical scale was used. Engell et al. graphically illustrated mean category values for euhydrated subjects as: thirst, 1.5; dry mouth, 1.1; feel tired, 0.1, and bad taste in mouth, 0.1. Standard errors of the means were also represented.

Engell et al. (1987) describe the Thirst Sensation Scale (TSS) which consists of 37 graded category scales paired with sensations or symptoms reported to be associated with thirst, as well as sensations and symptoms unrelated to thirst. Sensations and symptoms shown to be significantly associated with hypohydration were: dry mouth, bad taste in the mouth, dry

throat, feeling tired, feeling thirsty and thinking of drinking (plus several others).

No studies could be found which examine in detail the psychometric properties of the VAS for dehydration symptoms. In addition, no studies to date have used these VAS for dehydration research in cancer or other end-stage terminal illness. The VAS does represent, however, the most sophisticated self-report tool for the study of dehydration symptoms to date.

2.4 Confounding Variables in Dehydration Measurement

Age is the only variable found to modify the effect of fluid deprivation on the experience of dehydration symptoms. Older men experienced less thirst and dry mouth when compared to younger men for the same amount of fluid deprivation (Phillips et al., 1984). Although the power of the study was low, and no women were studied, age should be considered a possible confounder because of these results.

Medications such as tricyclic antidepressants, phenothiazines, opioids (narcotics), haloperidol, antihistamines, antispasmodics, diuretics and belladonna alkaloids are known to have significant effects on oral sensations, and should be considered possible confounding variables in the relationship between dehydration and the experience of symptoms (Twycross, 1984; White, Hoskin, Hanks and Bliss, 1988; Goodman and Gilman, 1975).

Other conditions known to alter the oral sensations include

local oral pathology such as tumour itself, candidiasis, stomatitis (radiation induced or otherwise), oral surgery and mouth care (Twycross, 1984).

No other possible confounding variables have been reported.

2.5 Summary of Literature Review

Although there are a number of descriptive and theoretical works on the topic of dehydration in those with advanced cancer, there are no research studies which examine the symptom experience of dying patients. Despite this lack of critical studies, there is extensive clinical use of intravenous fluids for the purpose of maintaining hydration and relieving the perceived symptoms of "terminal dehydration" and "suffering".

The measurement of dehydration in patients dying of cancer is extremely difficult due to the clinical effects of the malignancy itself, the ethical concerns of using accurate but invasive methodology and the lack of a non-invasive "gold standard". The measurement of fluid intake, serum sodium and serum osmolality have been reported as useful indicators of dehydration in previous studies of individuals without cancer.

The measurement of symptoms due to dehydration also, has not been extensively studied. Self-report tools such as the VAS have been used in other symptom investigation studies and have been found to be reliable and valid. There is only limited information available concerning the psychometric properties of VAS for dehydration symptoms.

Possible confounding factors which might alter the association between symptoms of dehydration and actual dehydration include: age, medications and oral pathology.

3.0 Design

3.1 Overview

A cross-sectional survey was conducted of all patients with advanced cancer admitted to the Palliative Care Units (PCU) of the Royal Victoria Hospital and the Montreal Convalescent Hospital Centre (Fig. 4). All patients in the PCU were eligible for entry into the study after meeting the inclusion criteria as outlined below. Once the assistant head nurse or designate provided permission for the researcher to approach the patient, a verbal explanation (Appendix 10.1) was provided and consent obtained (Appendix 10.2).

Patients were asked to complete the self-report VAS for thirst, pain, dry mouth, nausea, bad taste in mouth, fatigue and pleasantness of drinking, at the time of the initial visit and again twenty-four hours later for a measure of test-retest reliability (Appendix 10.3).

A single blood sample was drawn during that twenty-four hour period to measure sodium, osmolality, serum urea and glucose.

Patient descriptive information was obtained from the chart and included age (at last birthday), sex, site of primary malignancy, current medications, number of days in palliative care unit prior to interview and presence of oral disease.

The primary nurse caring for the patient on the day of the first patient-reported VAS was also asked to complete equivalent VAS reports as an observer rating of the patient's experience. This nurse also estimated the fluid intake of the patient during

the previous twenty-four hour period. Intake was categorized as one of: 0=0-249ml; 1=250-499ml; 2=500-749ml; 3=750-999ml and 4= >1000ml (Appendix 10.4). These categories were derived from a consensus approach among palliative care nurses.

The time, in days, from initial patient VAS reporting to death was assessed by record follow-up at weekly intervals. The records of those refusing or unable to participate were reviewed to compare with the study group.

3.2 Setting

The Palliative Care Unit of the Royal Victoria Hospital is a 16-bed ward in a 850-bed tertiary care urban teaching hospital. The unit admits patients with advanced terminal illness for the purposes of symptom control, respite care and terminal care. There is one principal attending physician and patients have access to all hospital services and consultants. Patients are generally admitted through referral from other hospital services, community referral or from the palliative care home care service.

The Palliative Care Unit of the Montreal Convalescent Hospital is a 21-bed ward within a rehabilitative and extended care urban hospital centre. The unit admits patients with advanced terminal illness primarily for the purpose of terminal care. Patients are referred from the greater Montreal environment and are generally not known to the hospital before admission.

3.3 Study Group

All patients admitted to the PCUs were considered. Although patients with diagnoses other than cancer are admitted, they represent less than 10 percent of the patient population. The units were visited three times weekly and the assistant head nurse, charge nurse or ward physician identified all potential study subjects. Those who met the inclusion criteria and who consented were entered (Fig. 4).

3.4 Inclusion Criteria

All patients admitted to the PCU were initially considered for entry if they met the following criteria:

1) age 18 years or over
2) diagnosis of malignancy for which cure-oriented therapy had been discontinued
3) estimated prognosis by attending physician of six weeks or less
4) ability to speak English or French
5) ability to understand, give consent and participate in the study as assessed by the assistant head or charge nurse and researcher (i.e. absence of confusional state and willingness to participate)

The estimate of prognosis was required in order to select those patients not admitted for respite care who were early in their disease and not likely to experience terminal dehydration during

this admission.

3.5 Sample Size

Sample size needed to detect a significant relationship between fluid intake and symptom could not be accurately predicted prior to undertaking this study. No previous research had been conducted to provide distribution estimates of the dehydration state symptoms.

Another difficulty in determining sample size arose from the lack of adequate formulae when multivariate techniques are used for the analysis. However, Tabachnick and Fidell (1989) state that there should be at least five times the number of cases as there are independent variables. In this study there were nine possible independent variables and therefore at least 45 subjects were needed.

Post-hoc power estimations were performed after the study was completed and can be found in section 4.3.

3.6 Instruments

One measure, consisting of seven questions, was administered twice to each subject. The questions consisted of four specific items directed at oral dehydration state symptoms: thirst, dry mouth, pleasantness of drinking and unpleasantness of the taste in the mouth. The remaining three items considered symptoms possibly associated with the dehydration state but more likely to be associated with the extent of the malignant disease: nausea,

fatigue and pain. Appendix 10.3 contains the visual analogue scales used to administer these seven questions. This same measure was used for the repeat assessment at 24 hours.

The nurse caring for the patients also completed the same 7-item VAS questionnaire. In addition, the nurse assessed mouth care and fluid intake of the subject using the fluid intake assessment sheet (Appendix 10.4).

Serum sodium, serum osmolality and urea were analyzed by the clinical laboratories of the Royal Victoria Hospital and the Montreal Convalescent Hospital Centre.

The remaining patient information was obtained from chart review: age, sex, primary diagnosis, medications, oral disease and time to death, in days, from entry into the study (Appendix 10.5).

3.7 Goals of the Analysis

The primary response variables were the VAS scores of the patients' reports of dehydration state symptoms. The predictor variables were fluid intake, serum osmolality, serum sodium and serum urea. Age, sex, primary tumour site, oral disease, medications and time to death were all treated as potential confounding variables or effect modifiers.

Univariate descriptive characteristics of the study sample were determined initially. These included the means and standard deviations of: the VAS scores, serum osmolality, sodium and urea, patient age, length of admission prior to entry into the study,

and time to death. Also included were the frequencies of: fluid intake, diagnostic groups, sex, oral disease and medications.

Reliability studies were then undertaken to evaluate the ability to use the 7-item questionnaire as a composite measure for dehydration state symptoms. For the patients' VAS reports this included: inter-item correlations, item-total correlations, stability correlations (test-retest correlations and intraclass correlation coefficients), Cronbach's alpha for internal consistency, inter-observer correlations (Pearson's R) and Difference Comparisons using the method of Bland and Altman (1986). Decisions regarding the use of a composite score were based on these reliability results.

Bivariate analyses were then performed to examine the relationship between the predictor variables and the response variable. Simple linear regression was used to study the continuous predictor variables (i.e. fluid intake, osmolality, sodium and urea), and confounding variables (age and days admitted prior to interview). In the case of the dichotomous categorical variables (sex, oral disease, medications and survival), a chi-square method was used. Those multiple categorical variables, fluid intake, mouth care and primary tumour diagnosis, were studied using analysis of variance. If significance was found, then a post-hoc comparison of means was performed.

All variables were then entered in a multiple regression modelling analysis. A backward elimination strategy for variable

selection was used. The analysis was performed with and without the use of dummy variables for the multiple categorical confounders.

3.8 Ethical Considerations

Clinical research involving patients who are dying is a relatively recent phenomenon. It follows closely the rapidly improving clinical knowledge about and care of terminally ill patients. This research brings special concerns to the methodology as maximizing the quality of remaining life for individuals is now the goal of clinical care. As a result, the burden to patients brought about by participation in research must be minimized and any opportunity to maximize quality of life through the research must be seized.

This protocol reflected these concerns in that the questionnaire was reduced to a simple seven item measure, requiring less than 5 minutes to complete. An opportunity to openly discuss symptom concerns with the researcher was provided to all participants. This type of discussion has been shown to be beneficial by several authors (Glaser & Strauss, 1965; Hamilton, 1985; Hinton, 1974). After obtaining the patient's consent the concerns were raised with the clinical team with the goal of reducing symptom distress.

Confidentiality and anonymity were assured. Patients were informed of the nature of the study, their ability to withdraw at any time and that their participation or lack of would not affect

their subsequent care.

The verbal description used by the researcher in approaching potential study subjects is found in Appendix 10.1. The consent to participation form is found in Appendix 10.2.

This study protocol was approved by the Palliative Care Service of the Royal Victoria Hospital and by the ethics committee of the Montreal Convalescent Hospital Centre.

4.0 Results

4.1 Study Population and Symptom Reporting

Subjects were recruited for this study during the period November 1989 to June 1990. One hundred and twenty-three patients were considered for participation. Fifty-two fulfilled all conditions necessary to enter. Of the 52 subjects who participated, 36 were able to repeat the questionnaire a second time. With respect to the laboratory analyses, blood was obtained from 51 of the 52 subjects for the assessment of sodium, osmolality and urea.

Table 1 outlines selected characteristics of the included and excluded subjects. There were several significant differences between the two groups. A list of the reasons for exclusion is found in Table 2.

As can be seen from this list, participants were inpatients longer before commencing the study, and survival time after study inclusion was also longer in this group. The proportion of individuals in the lower fluid intake categories was greater in those excluded. Mouth care was also more intensive in the excluded group. None of the remaining characteristics were found to be statistically significantly different between the two groups. One should note, however, the differences in the distribution of tumour types among patients.

The distribution of symptom scores reported by subjects can be found in Figure 5. The corresponding distribution of scores

as reported by the nurses are found in Figure 6. The mean VAS scores for patients ranged from a low of 24.0 for nausea to 61.8 for fatigue.

Table 3 shows the mean VAS scores for each symptom by fluid intake category. The laboratory results are found in Table 4.

4.2 Scale Development

Seven questions were chosen from the collection of symptoms thought to be associated with reduced fluid intake. These were determined by interviewing physicians, nurses and patients and from a review of the literature. Initial reliability analyses were performed to assess the usefulness of this 7-item questionnaire as a "composite" indicator of the symptoms associated with varying fluid intake. This analysis was necessary prior to the use of the composite score in the multivariate analyses.

Inter-item correlations were first estimated to see if any of the questions were so highly correlated that redundancy existed. Table 5 shows the highest interitem correlation to be 0.51 between thirst and dry mouth. Extremely low correlations or negative ones were found between pain and thirst, dry mouth, fatigue and pleasure in drinking; between dry mouth and nausea; between bad taste and pleasure in drinking; and between fatigue and pleasure in drinking. This suggests that pain and the pleasure obtained from drinking may be measuring different constructs than the other items.

Item-total correlations were determined and are found in Table 6. All correlations were positive with thirst, dry mouth, bad taste and fatigue most significantly so. Pain, pleasure in drinking and nausea had the poorest item-total correlations.

As a measure of stability, test-retest correlations were calculated. Only 36 subjects were able to repeat the symptom VAS a second time. All values were positive and significant (Table 7). The Pearson product moment correlations ranged from 0.83 for thirst to 0.47 for fatigue. As a second estimate of test-retest reliability, the intraclass correlation coefficients were calculated for the seven items (Table 8). Once again thirst had the highest value at 0.83.

The method of Bland and Altman (1986) was also used to evaluate stability. The difference between the symptom report at time one and that at time two was plotted on the Y-axis. The average of the two symptom report VAS scores was plotted on the X-axis. Ninety-five per cent of observations should lie within two standard deviations of the mean of the differences. This mean of the differences on the Y-axis should be zero or very close to it. Figure 7 demonstrates this technique for the assessment of repeatability for thirst. Because only 36 subjects were able to perform the repeat questionnaire, two or more values lying outside the two standard deviations results in less than ideal repeatability (i.e. more than 5% of values outside two standard deviations). When this method of stability analysis was performed for all seven items, only nausea met the above

criteria. The symptoms of thirst and fatigue were quite close with only six per cent of observations falling outside two standard deviations.

A paired t-test was also performed on the differences between the two reportings. None of the differences were found to be significantly different from zero.

Overall, stability was best for thirst by the method of test-retest correlation, intra-class correlations and paired t-test. It was somewhat less stable by the method of Bland and Altman where nausea performed best.

Inter-observer correlations between the symptom reporting by the subjects and that by the nurses were determined. All of these correlations were positive but none strongly so (Table 9). The highest correlations were for dry mouth, nausea and fatigue.

As Pearson product moment correlations again may not be the best estimate of inter-observer reliability, the method of Bland and Altman (1986) was also performed for this assessment. The mean score (between subject and nurse) was plotted against the difference between nurse report and the subject report. In this situation none of the symptoms were found to be stable in that all had more than five per cent of observations falling outside two standard deviations from the mean difference.

A paired t-test of the differences in the scores was also determined (Table 10). Significant differences from zero were found for the symptoms dry mouth, bad taste and pleasure in drinking.

It can be seen that these methods demonstrated that inter-observer reliability was not good for the items of specific interest: dry mouth, bad taste and the pleasure from drinking. All of these items were found to be reported significantly different by the nurses than by the subjects.

Finally, Cronbach's alpha was used to determine internal consistency. This was calculated for the entire 7-item questionnaire as well as various groupings of items. Table 11 gives the alpha value for the full questionnaire at 0.62. When thirst, dry mouth, bad taste and fatigue were combined the maximum possible alpha was realized at 0.72. The lowest alpha determined was 0.35 for the items pain, nausea and fatigue. Norman and Streiner (1990) have suggested that alpha values of at least 0.80 are required to ensure reliability for research studies.

As a result of these generally poor reliability results, further analysis was performed using only thirst as the outcome variable of choice. The selection of this item was determined by its principal clinical interest, its highest inter-item correlation, test-retest correlation and intraclass correlation coefficients.

4.3 Association of Symptoms and Predictors

Bivariate Analysis

All predictor variables (fluid intake, sodium, osmolality

and urea) and possible confounding variables that were continuous (age, days prior to study) were first regressed individually against the outcome variable, thirst. As Table 12 clearly shows, no variable was found to significantly predict thirst.

Results of the Student's t-test for differences in thirst ratings for the categories oral disease, drying medications and survival are found in Table 13. None were found to be significant. Because of the lack of variability in the item "drying medications" (only 1 of the 52 study subjects was not taking a "drying medication") it was dropped from the analysis at this point.

Results of the ANOVA calculations for the multiple categorical variables fluid intake and mouth care are shown in Table 14 and 15. Neither of these was predictive of thirst.

Multivariate Analysis

All variables were then entered as a full model into a multiple regression equation. The full model parameter estimates can be found in Table 16. None were found to be statistically significant in their association with thirst. When a backward elimination strategy for variable selection was used, again none attained significance. When dummy variables were substituted for the categories of mouth care regime, the significance of this possible confounder did not change.

Post-hoc Power Estimation

At the time this study was undertaken, no previous estimates of the VAS for the dehydration symptoms were available. As a result, sample size determination was based on reported estimates necessary for multivariate analyses. With 52 participants in symptom reporting, estimates of the standard deviations for each symptom permit post-hoc calculations of the power of the present study to detect specific differences in symptom reporting between the fluid intake groups.

By collapsing the fluid intake groups to two, <750ml/day and ≥750 ml/day, using alpha=0.05 and the standard deviation for each symptom, power estimates were determined (Table 17). For the principal outcome variable, thirst, the current study had a power of 76% to detect a difference of 20 mm on the VAS between high and low intake fluid groups. It had a 90% chance of detecting a 25 mm difference.

5.0 Discussion

5.1 Dehydration State Symptoms

The first objective of this study was to describe the distribution of these symptoms among participating subjects. Figure 5 depicts the distribution of the subjects' reporting of symptom distress. The experience of thirst was frequent with over 50% of subjects reporting scores of 50 mm or more on the VAS. Consistency in reporting other symptoms associated with thirst could be found in the proportion of people reporting the presence of dry mouth (65% >50 mm) and bad taste in the mouth (54% >50 mm).

Interpretation of this experience of significant symptom reporting is not, however, straightforward. At face value it appears the symptoms are moderately severe among palliative care patients. This may be true but it must also be asked how severe would these symptoms be among other hospitalized populations. Would, for instance, a hospitalized geriatric population experience the same severity of symptoms? No studies are available which quantify the reports of other such populations.

When the mean ratings of the symptoms are compared with those reported by the experimental subjects discussed previously, the palliative care subjects' ratings again appear quite high (Engell et al., 1987; Thompson et al.,1986; Thompson and Baylis, 1987). The euhydrated experimental subjects reported mean VAS scores for thirst over a range of 9-22 mm and the fluid deprived laboratory subjects reported rises in thirst ratings of 30-50 mm.

Thus, the fluid deprived ratings of thirst were in the order of 40-70 mm. This does not necessarily mean that the palliative care patients experience dehydration symptoms of a severity comparable to subjects deprived of fluid for 24 hours. It must be remembered that those experimental subjects knew they were participating in a fluid deprivation experiment. They knew that they should consider themselves euhydrated at the start of the study and become progressively more symptomatic as the study progressed. They were not blinded to the research hypothesis or to the intervention. This foreknowledge and the repeated measurements may account for the low baseline values of this group when compared to the palliative care population.

There was also a fundamental difference between this study and the experimental ones in the way questions were posed to subjects. In the former, each was asked to rate their symptom experience as averaged over the previous 24 hours. This is not a usual way to present these self-report questions. Averaging, it was hoped, would at least partially avoid the moment specific symptoms related to having just drunk, not eaten for three hours or just taken a bad tasting medication. Respondents in the experimental setting were asked to rate the symptom as they were experiencing it at that moment in time. Each method is appropriate for the study question, but limits comparisons of results.

Analysis of the fourth specific "symptom" related to fluid deprivation, that of the pleasure obtained from drinking,

revealed that almost 70% of subjects rated this at >50 mm. Although the reliability studies suggest this question may be concerned with a different construct, it may be that it is a construct of symptom relief rather than symptom distress. Encouragement could then be taken from the fact that so many report that drinking may relieve their symptoms. Many authors (Billings, 1985; Brown and Chekryn, 1989; Twycross and Lack, 1986 and Zerwekh,1983) have suggested that the frequent intake of small amounts of fluids might relieve symptoms. This particular questionnaire item gives support to their hypothesis.

Three other symptoms surveyed in this study were less directly related to decreased fluid intake. Eighty-three per cent of subjects reported nausea as less than 50 mm on the VAS. Indeed, 70% rated this symptom at <25 mm. Twycross (1986) reported that, among patients admitted to Sir Michael Sobell House (hospice), 40% experienced nausea or vomiting. This low prevalence among the study subjects may be due to the fact that only two who had bowel obstruction were able to be included, and that data were collected several days after admission when symptom control had already been initiated.

Fatigue was the most severe symptom among study subjects; 65% rated it at >50 mm and 42% at >75 mm. Comments from subjects reflected that their responses to this item covered both physical and emotional fatigue. "Without the ability to do the things I want to, I feel tired a lot and not willing to try". Fatigue seemed to encompass a feeling of tiredness as well as frustration

at being unable to do desired tasks.

Finally, pain was reported by almost 50% of study subjects as ≤25 mm. Only 10% reported it as >75 mm. The relief of pain has been a cornerstone of palliative care and the attention to this symptom is continuous. Patients are frequently asked about their pain experiences, to rate their pain and to comment on its relief. Responses may reflect a more discriminatory ability of patients with respect to this symptom. The dehydration symptoms may not be so commonly enquired about. The finding that 10% of patients report their pain rating at >75 mm is consistent with the literature (Billings, 1985 and Twycross, 1986).

5.2 Scale Development

The second objective of this study was to determine the psychometric properties of the composite measure of dehydration state symptoms. The ability to develop a reliable and valid scale which would measure a collection of such symptoms would have been advantageous for this study. Primarily, it would have allowed for several of the symptoms of concern to clinicians to have been accounted for in a single outcome variable. Only one statistical analysis would then have been necessary to explore the association between symptoms and predictor/confounding variables.

Because of the poor reliability results, each symptom had to be analyzed discretely as an outcome variable. Such multiple testing for association could have produced significant results

from the data set by chance alone. Subsequent corrections in probability estimates would have been necessary and cumbersome to interpret. To avoid this, thirst was chosen as the principal outcome variable.

Such poor reliability results may have been due to multiple contributory factors (Nunnally,1970). Errors due to inadequate or inappropriate sampling of content may have occurred. Only five of the seven items were specifically related to dehydration: thirst, dry mouth, bad taste, pleasure in drinking and fatigue. This is a low number of items to expect good reliability in the face of likely large amounts of measurement error due to subjective responses. This low number was necessary not to burden subjects who were so ill. It can be seen that the 7-item questionnaire was difficult enough to answer as only 69% were able to be retested. The items pain, nausea and pleasure in drinking may represent different constructs and reduced the reliability of the instrument.

The best Cronbach's alpha achievable was with the four items thirst, dry mouth, bad taste and fatigue. Such short scales often provide inadequate numbers of items to achieve good reliability. Nunnally (1970) provides a method to estimate the number of items required to attain a particular reliability given the existing scale's reliability. To achieve an alpha=0.84, eight items would be needed. To attain an alpha=0.89, twelve items would be needed. These are still relatively small numbers of items in a scale and may be possible in the palliative care

setting. One has to wonder, however, at relying simply on the mathematical properties of a reliability formula (Cronbach's alpha) and not the clinical basis of the item being measured in order to enhance reliability estimates.

Errors due to subjectivity of the test are highly possible in this situation. The reporting of symptoms is extremely personal and therefore subjective. This does not mean good reliability is not possible but may mean that it is harder to achieve. For example, Table 10 shows that the nurse observers consistently underestimate the subjects' experiences of thirst, dry mouth, bad taste and the pleasure obtained from drinking.

Fluctuations in the individual's state or the state of the testing environment may alter such a subjective report. These patients are often relatively well for a short period and can become quite sick quickly. This may account significantly for errors due to instability of the scores in that real clinical change is occurring.

Future studies must address these measurement error issues in order to improve the reliability of such symptom scales.

5.3 Association of Thirst and Predictors

The third objective of this study was to examine the associations between "dehydration state" symptoms and measures of dehydration. The composite scale score could not be used and thirst was, therefore, used as the principal symptom of interest.

The variables examined for association with this symptom

were fluid intake, sodium, osmolality and urea. Possible confounding variables considered were age, days in palliative care unit prior to interview, survival post interview, presence of oral disease, mouth care regime and the use of drying medications. Because of the lack of variability in the use of "drying medications", this item was dropped from the analysis for this study. This makes it impossible to draw conclusions about the contribution of medications to the oral sensations of thirst, dry mouth and bad taste in mouth.

Bivariate analyses did not reveal any significant association between the predictor variables and thirst. Even when fluid intake was collapsed to two categories for the post-hoc power estimations, no association was found. The multiple regression analysis also was not able to demonstrate significant associations. But what of the directions of the parameter estimates? Do they make "biologic" sense?

As fluid intake increases, so does the parameter estimate for thirst; that is, the greater the fluid intake, the greater the severity of thirst. This seems to be contrary to the belief that thirst should increase with fluid deprivation. However, palliative care clinicians argue that, in the situation of the dying, it may be that thirst and the desire to drink actually decrease as death nears. This argument is based on empirical observations in care.

The directions of the parameter estimates for sodium and osmolality are also in the opposite directions to usually

accepted norms. Here, as both laboratory measures increase, thirst decreases. The estimates are so near zero, though, it is hard to give the direction much significance. As urea increases, so does thirst, according to the parameter estimate in the regression model. This is compatible with current practice beliefs that, with fluid deprivation, both thirst and urea increase.

Thirst decreases with age in this model but, as the parameter estimate is a small one (-.08), a difference of 50 years represents a difference in thirst ratings of only 4.5 mm on the VAS. Phillips et al (1984) also found that the experience of thirst decreases with age.

The longer the duration of admission prior to interview was also associated with increased thirst. This may be accounted for by a longer duration of exposure to oral "drying medications". The presence of oral disease was found to be associated with a 13 mm increase in VAS scoring for thirst according to this model. This is the parameter estimate with the lowest p-value in the regression model. This trend provides evidence of oral disease as a logically postulated confounding variable in the association between thirst and fluid intake.

Finally, longer survival (greater than 14 days) is associated with less thirst. The longer survivors included those who had survived several months after participation in the study. These subjects may have been clinically quite well in comparison to those who survived less than 14 days and thus had a very

different experience of thirst.

Even after such careful consideration of the directions of the parameter estimates, one must remain very cautious about any interpretation when none were found significant in this model.

The question then remains, how confident can one be that an association was not missed by this relatively small sample? The power determinations were not possible for the multiple regression method but were for a dichotomized fluid intake variable, the predictor variable of most clinical interest. This study had a 76% chance of detecting a 20 mm difference or greater in symptom reporting between the high (≥750 ml/day) and low (<750 ml/day) fluid intake groups. Most clinicians would agree that this amount of difference would be a clinically significant difference. A difference of less than 10 mm would probably be clinically insignificant. The interval between 10 and 20 may be open to debate about its significance. Power estimates for this range were quite low for this study.

This study is not able to support those who believe that ensuring the intake of usual fluid volumes translates into the relief of thirst in these patients. It does provide some preliminary evidence that there are not large differences in thirst reporting between those who receive <750 ml/day and those who receive >750 ml/day.

Specific associations between certain different types of hypovolemic and dehydration states were not investigated in this study because extracellular fluid volume measurement was not

possible. Clinicians' decision-making regarding the use of assisted fluids in terminal care is not usually based on such volume estimations, but rather on the history of consistent poor fluid intake, physical signs and sodium, urea estimations.

Physical signs are quite unreliable in those with advanced malignancy. If, then, the decision to begin assisted fluids is based on the history of fluid intake and laboratory measures with the aim of reducing thirst, this study does not provide evidence to support this rationale.

Limitations of this study (discussed later) may restrict the ability to generalize beyond the study population to the dying cancer population in general. The absence of finding a positive association between fluid intake and thirst must, therefore, be interpreted with caution.

5.4 Limitations

Several features of this study limit the ability to generalize conclusions to the palliative care population in general and even limit the conclusions within the study population.

First, there were a number of characteristics of the study subjects which were different from that of the excluded population. Those included in the study had been resident in the palliative care unit longer prior to participation than those excluded. Second, fluid intake was significantly greater in the included group than the excluded. Third, mouth care was more

aggressive in the excluded group. And, lastly, survival after participation was longer in the included group.

All of these characteristics lead one to believe that the excluded population was probably sicker than the included. The longer prior duration of stay suggests that, in this cross-sectional study, those with longer duration of illness are more likely to be included in the study than those with aggressive short duration disease.

It is possible, then, that those excluded may experience the symptoms more severely than the study group. Countering this, though, is the increased attention to mouth care by the nurses. As well, there is no reason to think that the relationship between the amount of fluid taken in and symptoms is different in the sicker population.

The number of confounding variables considered in this study was limited by the difficulty in recruiting adequate numbers of subjects. Others to consider include fever, symptomatic diabetes mellitus, diabetes insipidus and the chronicity of fluid deprivation.

The small number of subjects participating in the study also limits generalizability. Only 52 of 123 potential subjects or 42% were entered. These small numbers also make multivariate methods more difficult to use. A much larger sample size would have improved the power of the study and, hence, confidence in the conclusions.

Finally, of critical importance in this study, the method of

fluid intake assessment was crude. It relied on an estimate made by the nurse based on observations during care. An accurate 24-hour intake would provide a continuous variable providing much more information for analysis.

5.5 Implications for Future Research

This study has provided the first estimates of the severity and distribution of dehydration symptoms in the dying. As a direct result, estimates of sample size can now be predicted for a wide range of future studies.

Replication of this study using a larger group of subjects would improve its power. To obtain a power of 0.80 to detect a 10 mm difference in VAS reporting of symptoms (between high and low fluid intake groups), approximately 250 subjects would be needed.

Improving the questionnaire by searching for more accurate dehydration symptom content questions and, perhaps, by increasing the number of items would enhance reliability. Measuring fluid intake as a continuous variable might also reduce measurement error. Expansion of the sample size would permit an expansion of the number of possible confounding variables to consider in any future regression model.

Comparison studies to describe the symptom experience of other populations, such as the hospitalized geriatric population or outpatient cancer patients, would add much to our understanding of suffering in the palliative care patients when

compared with others.

Intervention trials for the relief of symptoms may also be conducted now as estimates of the standard deviations of the reported symptoms have been determined. Open to such methodology would be the use of intravenous fluids, mouth care regimens and variations in the use of anticholinergic medications.

Prospective longitudinal studies could examine the association between the severity of the symptoms and proximity to death.

6.0 Conclusion

This study has provided the first quantitative estimate of the experiences of dehydration state symptoms in those with advanced cancer. The results demonstrate that the symptom of fatigue was rated most severely. Then in decreasing order of severity are: dry mouth, bad taste, thirst, pain and nausea. Four symptoms are thus rated as being more severe than pain and nausea. Clinicians should take pride in the ability to reduce pain and nausea to such low reported levels. However, this study shows that attention must also be directed at developing a deeper understanding of other symptoms. There may be a need to relieve these symptoms more adequately but, before one can say this, the experience of this population must be compared to others not expected to have these symptoms.

The ability to relieve the symptoms of thirst and dry mouth with small sips of water as suggested by palliative care clinicians has been supported by the evidence in this study where patients have reported the pleasure they receive from drinking.

The 7-item symptom scale proposed as an index of dehydration state symptoms has shown promise for future development. Although reliability estimates were not satisfactory for use in this study, the estimates were such that improvement should be achievable. Internal consistency, stability and inter-item reliability measures were moderately good.

Further exploration of validity would also be helpful. Ways to examine this may require novel methods of content and criteria

validation as no comparable measures exist.

No association could be shown between thirst, the primary symptom outcome of interest, and fluid intake. Analysis using both regression methodology controlling for confounding variables and simple analyses using the dichotomized fluid intake categories resulted in the absence of demonstrable association. This supports palliative care clinicians' claim that fluid intake is unlikely to be a significant determinant of distress due to thirst in those with cancer near death.

Also supportive of palliative care beliefs is the lack of association shown between the symptom of thirst and the biochemical measures in this study: sodium, osmolality and urea. Indeed, many will be surprised at the virtually normal distribution of these laboratory values.

Finally, this study breaks new ground in providing vital new quantitative information to begin a more in depth explanation of the symptom distress of reduced fluid intake in the dying patient. By combining this with other methods of inquiry to enhance our understanding of the ethical, symbolic and moral nature of this issue, we will have begun to unravel a complex and controversial element of comfort care.

7.0 References

Bailar, J. and Smith, E. (1986). Progress against cancer. The New England Journal of Medicine, 314, 1226-1232.

Behnke, A. and Wilmore, J. (1974). Evaluation of body build and composition. Englewood Cliffs, NJ: Prentice-Hall.

Billings, A. (1985). Comfort measures for the terminally ill: Is dehydration painful? Journal of the American Geriatrics Society, 33, 808-810.

Bland, J.M. and Altman, D.G. (1986). Statistical methods for assessing agreement between two methods of clinical measurements. Lancet, Feb.8, 307-310.

Brown,P. and Chekryn, J. (1989). The dying patient and dehydration. The Canadian Nurse, May, 14-16.

Burge, F., King D. and Willison, D. (1990), Intravenous fluids and the hospitalized dying: A medical last rite? Canadian Family Physician, 36, 883-886.

Callahan, D. (1986). Public policy and the cessation of nutrition. In J. Lynn (Ed.), By no extrordinary means. Bloomington, IN: Indiana University Press.

Campbell-Taylor, I. and Fisher, R. (1987). The clinical case against tube feeding in the palliative care of the elderly. Journal of the American Geriatrics Society, 35, 1100-1104.

Canadian Cancer Society, (1988) Canadian Cancer Statistics Toronto, Canada.

Dunagan, W. and Ridner, M. (1989). Manual of medical therapeutics, Toronto: Little, Brown and Company.

Engell, D., Maller, O., Sawka, M., Francesconi, R., Drolet, L., and Young, A. (1987). Thirst and fluid intake following graded hypohydration levels in humans. Physiology and Behavior, 40, 229-236.

Fleiss, J.L. (1986). The design and analysis of clinical experiments. New York: John Wiley and Sons, Inc.

Flynn, A. and Stewart, D. (1979). Where do cancer patients die? Journal of Community Health, 5,126-130.

Freyd, M. (1923), The graphic rating scale. Journal of Educational Psychology, 14, 83-102.

Gelenberg, A., Wojcik, J., Newell, C., Lamping, D. and Spring, B., (1985). A double-blind comparison of clovoxamine and amitriptyline in the treatment of depressed outpatients. Journal of Clinical Psychopharmocology, 5, 30-34.

Glaser, B. & Strauss, A. (1965). Awareness of dying. Chicago: Aldine.

Goodman, L.S. and Gilman, A. (1975). The pharmacological basis of therapeutics. Toronto: Collier MacMillan Canada Ltd.

Hamilton, J. (1985). Comfort on a palliative care unit: The client's perspective. Thesis. McGill University: Montreal.

Hinton, J. (1972). Dying. England: Penguin.

Huskisson, E. (1974). Measurement of pain. Lancet, 2, 1127-1131.

Isselbacher, K., Adams, R., Braunwald, E., Petersdorf, R. and Wilson, J. (1980). Harrison's principles of internal medicine, Toronto: McGraw-Hill Book Company.

Katz,B., Zdeb, M. and Therriault, G. (1979). Where people die. Public Health Reports, 94, 522-527.

Lachin, J.M. (1981). Introduction to sample size determination and power analysis for clinical trials. Controlled Clinical Trials, 2, 93-113.

Lukaski, H., Johnson, P., Bolonchuk, W. and Lykken, G. (1985). Assessment of fat-free mass using bioelectrical impedance measurements of the human body. The American Journal of Clinical Nutrition, 41, 810-817.

McCorkle, R. (1987). The measurement of symptom distress. Seminars in Oncology Nursing, 3, 248-256.

McCorkle, R. and Young, K. (1978). Development of a symptom distress scale. Cancer Nursing, October, 373-378.

McDowell, I. and Newell, C., (1987). Measuring health: A guide to rating scales and questionnaires. New York: Oxford University Press.

Micetich, K., Steinecker, P. and Thomasma, D. (1983). Are intravenous fluids morally required for a dying patient? Archives of Internal Medicine, 143, 975-978.

Norton, W. and Lack, S. in Twycross, R. and Ventafridda, V. (1979). The continuing care of terminal cancer patients. Toronto: Pergamon Press.

Nunnally, J.C. (1979). Introduction to psychological measurements. Toronto: McGraw-Hill Book Co.

Oliver, D.J. (1984). Terminal dehydration. Lancet,ii, 631.

Phillips, P., Rolls, B., Ledingham, J., Forsling, M. Morton, J., Crowe, M. and Wollner, L. (1984). Reduced thirst after water deprivation in healthy elderly men. The New England Journal of Medicine, 311, 753-759.

Printz, L. (1988). Is withholding hydration a valid comfort measure in the terminally ill? Geriatrics, 43, 84-88.

Ramsey, P. (1978). Ethics at the edges of life. New Haven: Yale University Press.

Revill, S., Robinson, J., Rosen, M., and Hogg, M. (1976). The reliability of a linear analogue for evaluating pain. Anaesthesia, 31, 1191-1198.

Rhodes, V., and Watson, P. (1987). Symptom distress- The concept: past and present. Seminars in Oncology Nursing, 3, 242-247.

Rolls, B., Wood, E., Rolls, T., Lind, H., Lind, W., and Ledingham, J. (1980). Thirst following water deprivation in humans. American Journal of Physiology, 8,R476-R482.

Scott, J., and Huskisson, E. (1976). Graphic representation of pain. Pain, 2, 175-184.

Siegler, M. and Weisbard, A. (1985). Against the emerging stream: Should fluids and nutritional support be discontinued. Archives of Internal Medicine, 145, 129-131.

Streiner, D.L. and Norman, G.R. (1989) Health measurement scales. A practical guide to their development and use. New York: Oxford University Press.

Tabachnick, B and Fidell, L. (1989). Multivariate statistics. New York: Harper and Row.

Thompson, C., Bland, J., Burd, J. and Baylis, P. (1986). The osmotic thresholds for thirst and vasopressin release are similar in healthy man. Clinical Science, 71, 651-656.

Thompson, C., and Baylis, P. (1987). Thirst in diabetes insipidus: clinical relevance of quantitative assessment. Quarterly Journal of Medicine, 65(246), 853-862.

Twycross, R., and Lack, S., (1986). Control of alimentary symptoms in far advanced cancer. New York: Churchill Livingstone.

Twycross, R., (1988). Symptom control in terminal cancer: lecture notes. Oxford: Sir Michael Sobell House.

Wigle, D., Mao, Y., Semenciw, R., and Morrison, H. (1986). Cancer patterns in Canada. Canadian Medical Association Journal, 134, 231-235.

White,I., Hoskin, P., Hanks,G. and Bliss, J. (1988). Does morphine cause dry mouth? Abstract from: European Congress on Palliative Care. Milan, Italy: Fondazione Floriani.

Zerwekh, J. (1983). The dehydration question. Nursing, 83, 47-51.

Figure 1: Self-Report Measures

Likert Format:

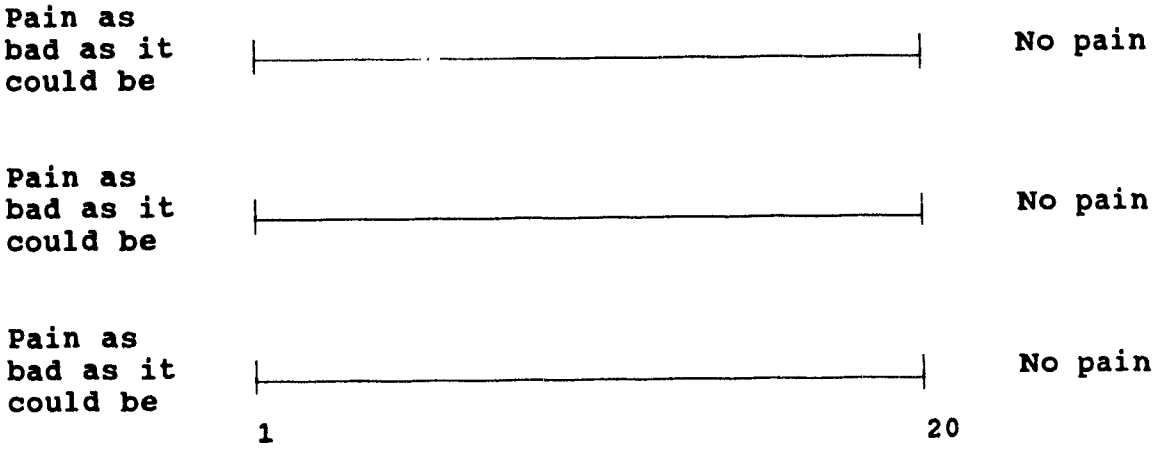
Nausea

1	2	3	4	5
I seldom feel any nausea at all	I am nauseous once in a while	I am often nauseous	I am usually nauseous	I suffer from nausea almost continually

(McCorkle, R. and Young, K., 1978)

Visual Analogue Scales:

Pain



(Scott, J. and Huskisson, E., 1976)

Figure 2: Visual Analogue Scale for Pain

Pain: Place a vertical mark on the line which best describes your pain.

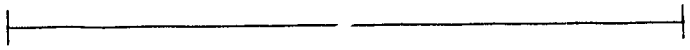
(Huskisson, E., 1974)

Figure 3: Visual Analogue Scales: Vertical vs. Horizontal

Pain as bad as it could be

No pain

Pain as bad as it could be



No pain

(Scott, J. and Huskisson, E., 1976)

Figure 4: Sampling Procedure

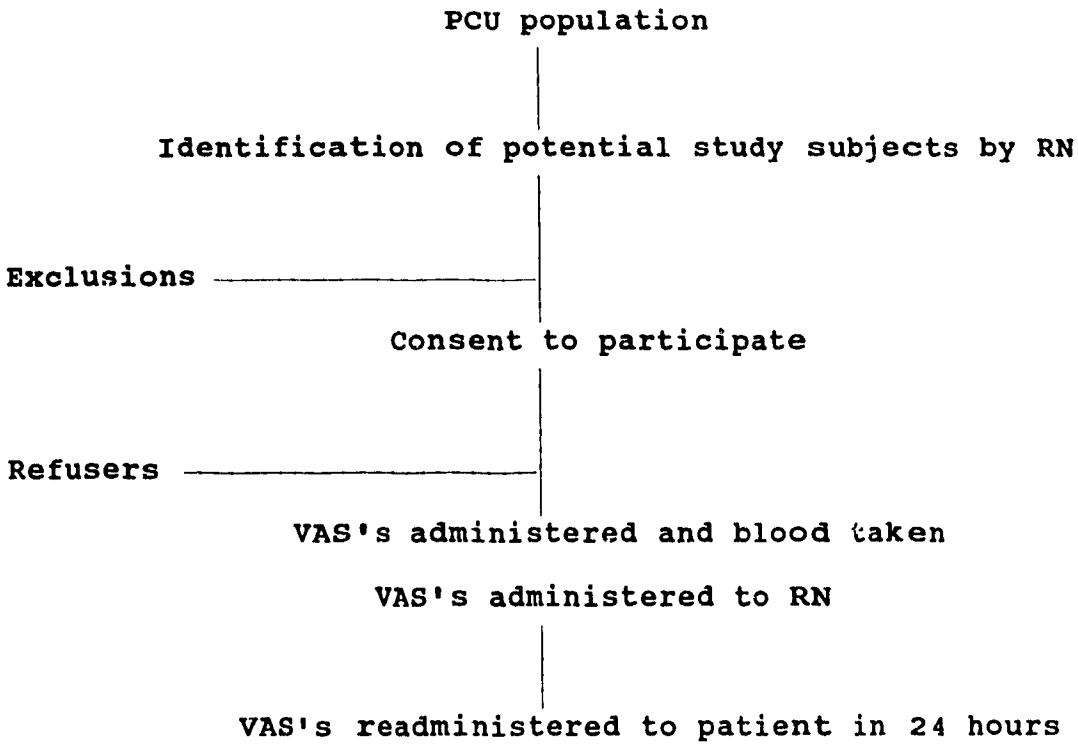
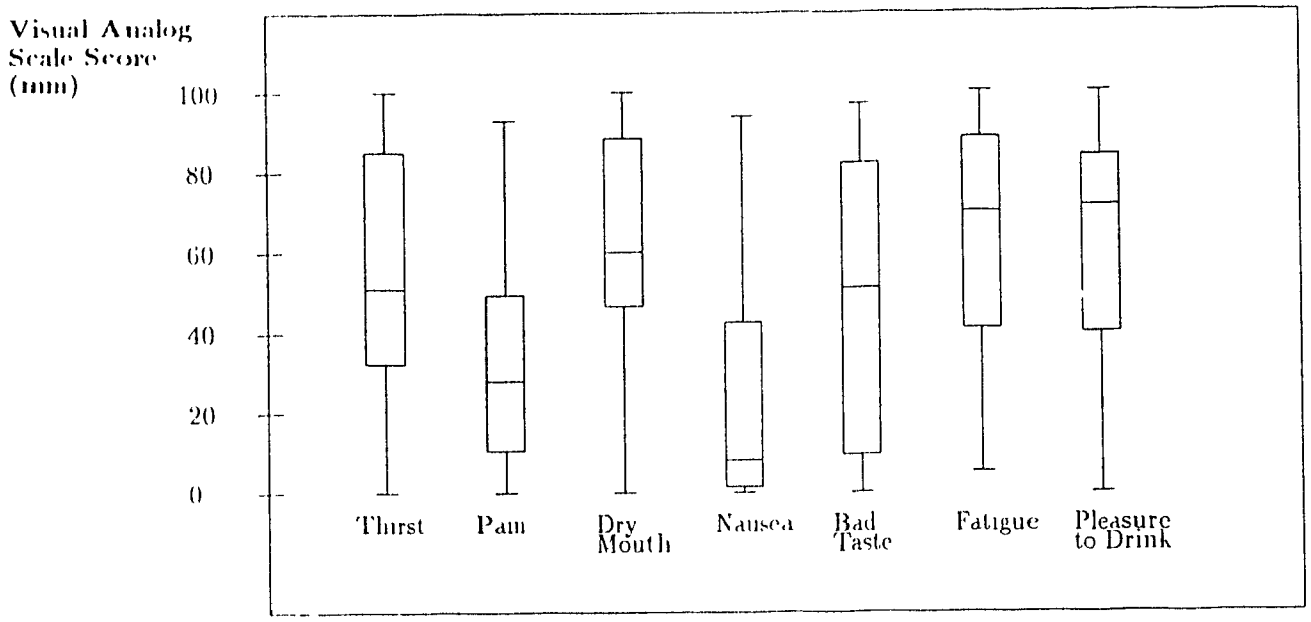
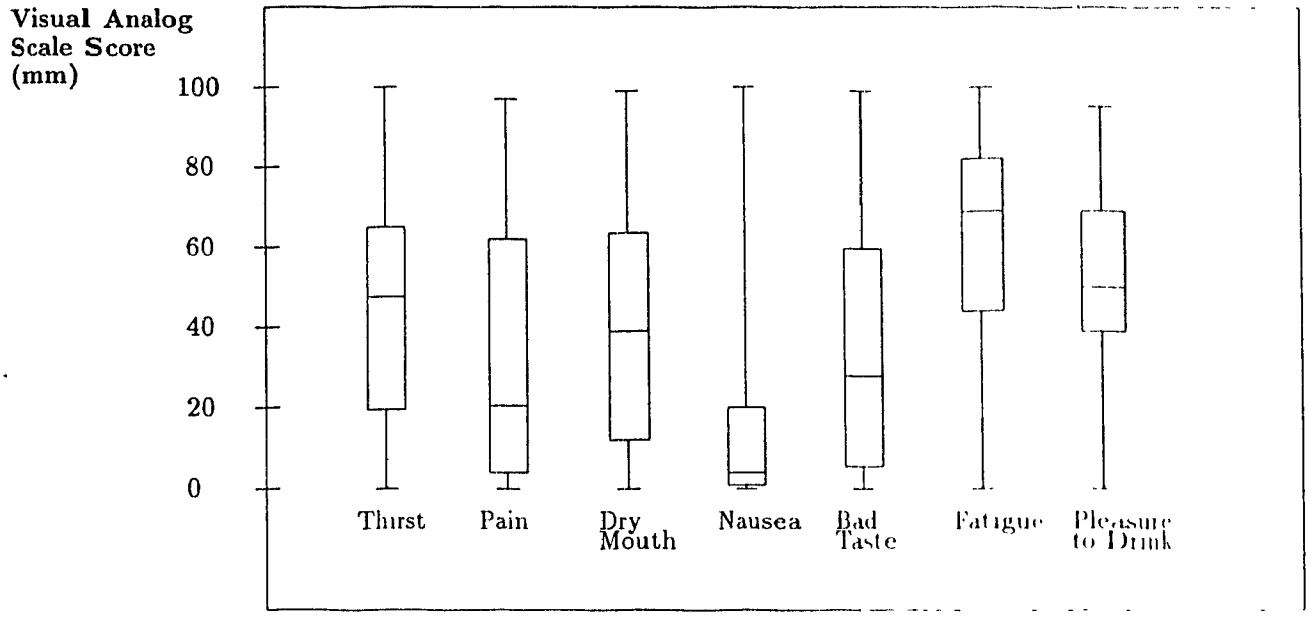


FIGURE 5: DISTRIBUTION OF SUBJECT VAS SCORES FOR SELECTED SYMPTOMS



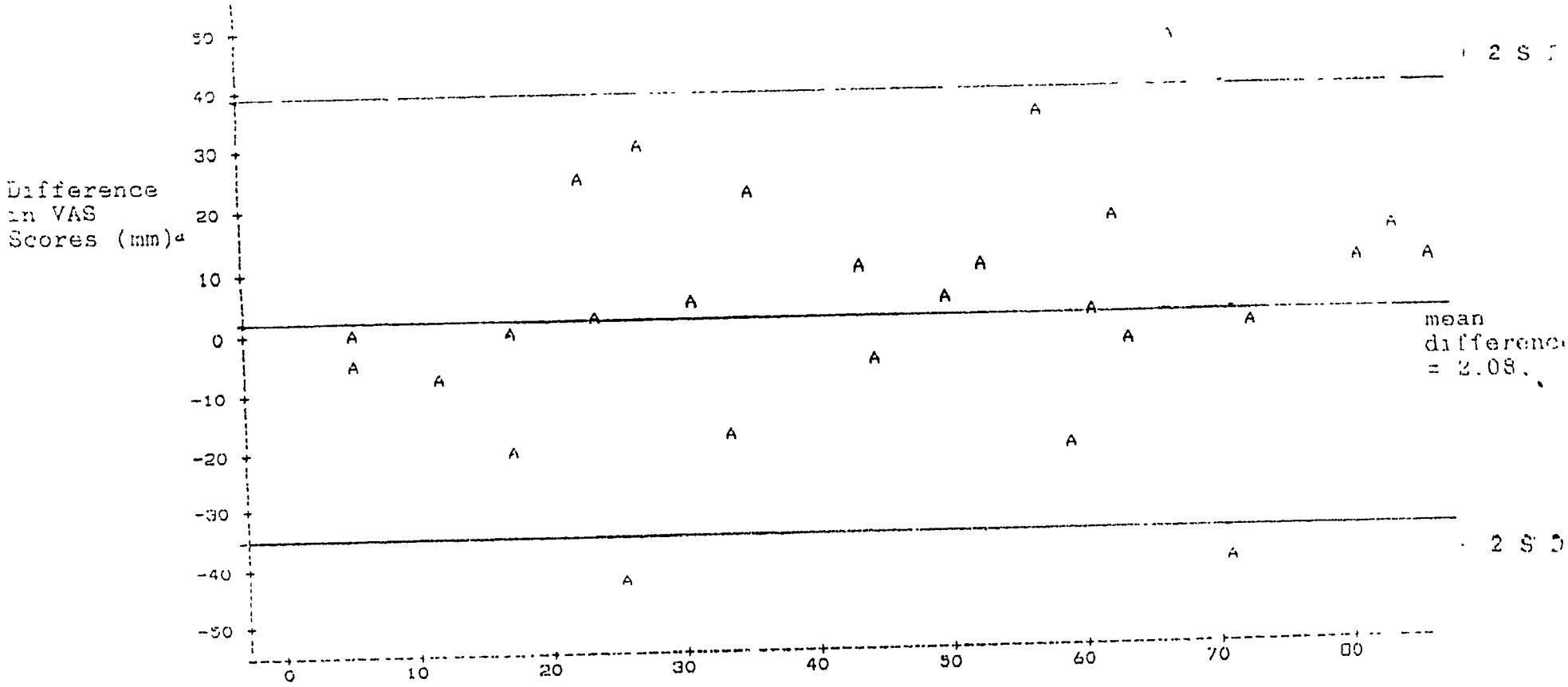
Legend The distribution of responses of subjects to each item is represented by a box plot The horizontal lines from top to bottom are the 100^{th}, 75^{th}, 50^{th} (median), 25^{th}, and 0^{th} percentiles of subject responses The 25^{th} to 75^{th} percentiles of responses are enclosed in the box, and the line within the box is the median (50^{th} percentile)

FIGURE 6: DISTRIBUTION OF NURSE VAS SCORES FOR SELECTED SYMPTOMS



Legend The distribution of responses of subjects to each item is represented by a box plot. The horizontal lines from top to bottom are the 100^{th}, 75^{th}, 50^{th} (median), 25^{th}, and 0^{th} percentiles of subject responses. The 25^{th} to 75^{th} percentiles of responses are enclosed in the box, and the line within the box is the median (50^{th} percentile).

Figure 7: Difference in VAS Scores for Thirst (time 1-time 2) vs. Mean VAS Scores for Thirst *



* n=36 as sixteen subjects were unable to participate in repeat testing

a time 1 - time 2 = difference in VAS Score

Table 1: Selected Characteristics of the Study Population

Characteristic	Included n=52	Excluded n=71	Test Statistic[a]
Mean age (years)	64.4	64.1	t=0.10
Sex			
females	26(50%)	32(45%)	
males	26(50%)	39(55%)	X^2=0.29
Length of stay prior to study			
≤ 5 days	26(50%)	50(70%)	
> 5 days	26(50%)	21(30%)	X^2=5.30*
Survival post-study (in days)			
≤ 14 days	14(27%)	41(58%)	
> 14 days	38(73%)	30(42%)	X^2=11.54**
Fluid intake category			
< 250 ml/day	5(10%)	23(32%)	
250-499 ml/day	12(23%)	12(17%)	
500-749 ml/day	7(13%)	10(14%)	
750-999 ml/day	14(27%)	12(17%)	
≥ 1000 ml/day	14(27%)	14(20%)	X^2=9.55*
Primary tumor site			
gastrointestinal	14(27%)	26(37%)	
lung	11(21%)	10(14%)	
genitourinary	10(19%)	11(15%)	
breast	4(8%)	7(10%)	
CNS	2(4%)	5(7%)	
other	11(21%)	12(17%)	X^2=5.98

[a] * denotes p<0.05 and ** denotes p<0.01

Table 1(continued):

Mouth care regime			
no assisted care	23(44%)	13(18%)	
assisted 1-4x/day	25(48%)	35(49%)	
assisted >4x/day	4(8%)	23(32%)	X^2=15.24**
Oral disease			
present	10(19%)	21(30%)	
absent	42(81%)	50(70%)	X^2=1.71
Oral "drying" medications			
present	51(98%)	64(90%)	
absent	1(2%)	7(10%)	Fisher's exact test[b]

[b] no significance found

Table 2: Reasons for Exclusion from the Study

Reason	Frequency (%)
Confusion	20 (28)
Too weak to participate	17 (24)
Drowsiness/coma	13 (18)
Language barrier	7 (10)
Died too quickly to participate	5 (7)
Refused	5 (7)
Aphasia	2 (3)
Severe anxiety	1 (1.5)
Severe agitation	1 (1.5)
	71 (100)

Table 3: Mean VAS Subject Symptom Reports by Fluid Intake Category

Item	Fluid Intake Category (ml/day)				
	0-249 n = 5	250-499 12	500-749 7	750-999 14	>1000 14
Thirst	67.2	46.1	51.7	46.3	64.0
Pain	37.8	32.9	46.1	34.6	25.1
Dry Mouth	60.2	61.3	61.6	58.5	59.6
Nausea	48.2	30.7	14.0	11.1	27.4
Bad Taste	58.0	58.4	45.3	42.6	37.2
Fatigue	73.2	62.0	78.3	53.9	57.3
Pleasure to drink	56.2	56.3	73.7	66.5	56.9

	All Fluid Categories 52	S.D.*
Thirst	53.8	30.6
Pain	33.5	27.7
Dry Mouth	60.0	30.4
Nausea	24.0	30.3
Bad Taste	46.6	33.3
Fatigue	61.8	28.7
Pleasure to drink	61.6	31.1

* Standard deviation of symptom score for all fluid categories combined.

Table 4: Results of Laboratory Measures

Item	Mean	Median	S.D.	Subject Range	Normal Range
Sodium (mmol/l)	134.5	136	6.46	116-147	132-145
Osmolality (mOsm/l)					
All	282.3	282	12.65	251-313	275-300
Directly measured	281.1	282	10.80	251-306	275-300
Urea (mmol/l)	6.70	5.8	2.32	2.1-24.6	2.1-8.2

Table 5: Inter-item Correlations

	Thirst	Pain	Dry Mouth	Nausea	Bad Taste	Fatigue	Pleasure to drink
Thirst	1.00						
Pain	-.04	1.00					
Dry Mouth	.51**	.03	1.00				
Nausea	.06	.12	.06	1.00			
Bad Taste	.25	.12	.43*	.34*	1.00		
Fatigue	.35*	.08	.39*	.25	.45*	1.00	
Pleasure to drink	.22	.00	.17	.12	.00	-.02	1.00

* denotes $p<0.01$
** denotes $p<0.001$

Table 6: Item-total Correlations

Item	Correlation	P-value
Thirst	0.41	0.003
Pain	0.09	0.54
Dry mouth	0.50	0.000
Nausea	0.28	0.05
Bad taste	0.48	0.000
Fatigue	0.46	0.000
Pleasure to drink	0.14	0.33

Table 7: Test-retest Pearson Correlations (48 hours)*

Item	Correlation
Thirst	0.83
Pain	0.57
Dry mouth	0.48
Nausea	0.48
Bad taste	0.61
Fatigue	0.47
Pleasure to drink	0.69
Total	0.79

* n=36

Table 8: Intraclass Correlation Coefficients for Test-retest Subject Symptom Reports

Item	Intraclass Correlation Coefficient
Thirst	0.83
Pain	0.57
Dry mouth	0.51
Nausea	0.45
Bad taste	0.64
Fatigue	0.48
Pleasure to drink	0.69

Table 9: Inter-observer Correlations for VAS Symptom Reporting between Subject and Nurse

Item	Correlation	P-Value
Thirst	0.12	0.37
Pain	0.26	0.06
Dry mouth	0.46	0.000
Nausea	0.44	0.001
Bad taste	0.29	0.03
Fatigue	0.32	0.02
Pleasure to drink	0.27	0.05
Total	0.23	0.10

Table 10: Results of Paired T-Test of Subject-Nurse VAS Symptom Rating

Item	Mean VAS Difference*	T-Statistic	P-Value
Thirst	8.59	1.61	0.11
Pain	0.38	0.08	0.99
Dry mouth	20.35	4.79	0.00
Nausea	5.81	1.33	0.19
Bad taste	13.06	2.54	0.01
Fatigue	0.90	0.19	0.85
Pleasure to drink	11.98	2.53	0.01

* Subject VAS Score - Nurse VAS Score averaged over the 52 subjects.

Table 11: Estimates of Internal Consistency using Cronbach's Alpha

Items in scale	Cronbach's Alpha
All seven	0.62
Thirst,Dry,Taste,Drink	0.58
Thirst,Dry,Taste	0.66
Thirst,Dry,Nausea,Taste,Fatigue	0.69
Thirst,Dry,Taste,Fatigue	0.72
Pain,Nausea,Fatigue	0.35

Table 12: Simple Linear Regression

Item	Parameter	SE	I	P
Fluid Intake	1.47	3.18	0.46	0.65
Sodium	-0.85	0.67	-1.28	0.21
Osmolality	-0.13	0.35	-0.37	0.71
Urea	1.22	1.11	1.10	0.28
Age	0.08	0.28	0.28	0.78
Days to Interview	0.02	0.12	0.16	0.88

Table 13: Results of Student T-Test of Thirst Reporting by Oral Disease Presence, Use of Drying Medications and Survival

Category		n	Mean Thirst Score	T-Statistic	P-Value
Oral disease	+	10	66.0	1.42	0.16
	-	42	50.9		
Drying Medications	+	51	54.7	1.6	0.11
	-	1	5.0		
Survival	≤14d	14	61.5	1.11	0.27
	>14d	38	50.9		

Table 14: ANOVA Table for Thirst Rating by Fluid Intake

Source	DF	SS	MS	F	P>F
Fluid	4	3874.48	968.62	1.03	0.39
Error	47	44010.75	936.40		

Table 15: ANOVA Table for Thirst Rating by Mouth Care Regime

Source	DF	SS	MS	F	P>F
Mouth Care	2	429.38	214.69	0.22	0.80
Error	49	47455.85	968.49		

Table 16: Multiple Regression Analysis: Full Model

Item	Parameter Estimate	SE	T	P-Value
Fluid	2.23	4.107	0.54	0.59
Sodium	-1.27	1.391	-0.92	0.37
Osmolality	0.24	0.742	0.32	0.75
Urea	0.58	1.512	0.38	0.70
Age	-0.14	0.328	-0.41	0.68
Days prior to interview	0.11	0.153	0.72	0.48
Oral Disease	-14.96	12.527	-1.19	0.24
Mouth Care	0.61	9.901	0.06	0.95
Survival	-9.50	12.989	-0.73	0.47

Table 17: Post-hoc Power Estimations by Symptom when Fluid Intake Dichotomized*

Item	Power Estimate (as proportion)			
	μ = 10mm	20mm	25mm	30mm
Thirst	0.32	0.76	0.90	0.97
Pain	0.36	0.83	0.95	0.99
Dry mouth	0.32	0.76	0.91	0.97
Nausea	0.32	0.77	0.91	0.97
Bad taste	0.29	0.70	0.86	0.95
Fatigue	0.35	0.81	0.93	0.98
Pleasure to drink	0.31	0.75	0.89	0.97

* After Lachin, JM 1981
where

$$Z_\beta = \frac{|\mu| \sqrt{n} - Z_\alpha \sigma \sqrt{(Q_e^{-1} + Q_c^{-1})}}{\sigma \sqrt{(Q_e^{-1} + Q_c^{-1})}}$$

Z_α = 1.645
μ = difference to be detected in mm on VAS
n = total = 52
Z_β = power statistic
Q_e = sample fraction in first group = 28/52
Q_c = sample fraction in second group = 24/52
σ = standard deviation for each symptom e.g. thirst σ=30.6mm

10.0 Appendices

Appendix 10.1 Verbal Explanation

My name is Dr. Fred Burge. I am a graduate student of the Faculty of Medicine at McGill University and I am studying symptoms patients experience.

I am wondering if I could take about five minutes of your time to tell you about this project and what it involves with the understanding that you need not make a decision to participate at this time.

Doctors and nurses are interested in relieving your symptoms. This is particularly important in the palliative care unit. It is important for the physician and nurses to understand these symptoms as the patient truly perceives them and not how they think the patient experiences them.

If you agree to participate in the study, you will be asked to answer seven brief questions on two occasions taking approximately five minutes to complete. Also, one blood sample will be required which, if possible, will be taken at the time of any usual blood tests ordered by your physician.

Your decision whether to take part or not will in no way affect your care here.

If you are willing, we can arrange a time convenient for you to ask the questions.

Appendix 10.2 Consent Form (English)

The research study has been explained to me. I understand that I will be asked seven questions about symptoms on two occasions, 24 hours apart. I understand I will have one blood test during this study.

This study is part of medical research at McGill University. The researcher has permission from the Palliative Care Service of the Royal Victoria Hospital to ask patients to participate. The decision to take part in the study will in no way affect my care here. I understand the researcher is not connected with the Palliative Care Unit except as a research student.

My participation in the study is voluntary. I am free to withdraw my consent and discontinue taking part in the project at any time, without explanation. Any questions I have about the project will be answered.

On the basis of the above statements, I agree to participate in this project on symptoms.

_____ _____

Participant's signature Date

_____

Witness

Appendix 10.2 Consentement pour l'Étude des symptômes (français)

On m'a déjà expliqué cette étude de recherche. Je comprends qu'on va me poser sept questions au sujet des symptômes a deux occasions à 24 heures d'intervalle. Je comprends que je subirai une prise de sang pendant cette étude.

Cette étude fait partie de la recherche medicale à l'université McGill. Le service des soins Palliatifs de l'hôpital Royal Victoria a permis au chercheur de demander la participation des patients. Ma décision de participer n'aura aucune influence sur mes soins. Je comprends que le chercheur n'est lié au service des soins Palliatifs qu'en capacité d'étudiant en recherche.

Ma participation dans l'étude est volontaire. Je peux retirer ma permission et cesser de participer au projet n'importe quand sans expliquation. On répondra à toutes mes questions au sujet du projet.

Par suite de cette déclaration, je participerai à ce projet.

_____ _____

Participant(e) Date

_____

Témoin

Appendix 10.3 Dehydration Symptom Questionnaire

1. On average, how thirsty have you felt during the last 24 hours?

Not at all thirsty _____ Extremely thirsty

2. On average, how would you rate the pain you have experienced during the last 24 hours?

No pain _____ Worst pain imaginable

3. On average, how dry has your mouth been during the last 24 hours?

Not at all dry _____ Extremely dry

4. On average, how nauseated have you been during the last 24 hours?

Not at all nauseated _____ Extremely nauseated

5. On average, how unpleasant has the taste been in your mouth during the last 24 hours?

Not at all unpleasant _____ Extremely unpleasant

6. On average, how fatigued have you been during the last 24 hours?

Not at all fatigued _____ Extremely fatigued

7. On average, how pleasant has it been to drink during the last 24 hours?

Not at all pleasant _____ Extremely pleasant

Appendix 10.4 Nursing Assessment Form

Estimated total fluid consumption from all sources for this patient during the last 24 hours.

Less than 250 ml (8 ounces)	____0	e.g. tea/coffee 180 ml 6 oz
250 - 499 ml (8 - 16 ounces)	____1	
500 - 749 ml (16 - <24 ounces)	____2	juice 120 ml/4 oz
750 - 999 ml (24 - <32 ounces)	____3	
1000 ml or more (> 32 ounces)	____4	

Mouth Care Regimen

Please pick the mouth care regimen which best describes this patient: (check one only)

self-care/no nurse assistance	____0
nurse/family assistance 1-4 times/day	____1
nurse/family assistance 5 or more times/day	____2

Please describe the mouth care regimen for this patient currently (i.e. what solutions/equipment you use and how frequently it is performed):

_____

_____

_____

Are family members also doing mouth care? yes ____ no ____
If yes, how often? _____

Appendix 10.5 Demographic Assessment Form

Subject number _____

Interview date (d,m,y) _____

Admission date to PCU (d,m,y) _____

Admission date to hospital (d,m,y) _____

Location of subject: previous to interview site _____
at time of interview _____

Age (at last birthday) _____

Sex _____

Primary Malignancy _____

Medications (in last 24 hours)

_____ _____ _____

_____ _____ _____

_____ _____ _____

Oral disease/pathology Yes/No If yes, what?

_____

Subject: Included ____ Excluded ____ why _____

Refused ____

Sodium ____ Urea ____

Osmolality ____ Glucose ____

Date of Death (d,m,y) _____

Appendix 10.6 Coding Sheet

1. Subject ID _____

2. Status: Included 0, Refused 1, Excluded 2: ____

3. Location: RVH PCU 0, Other 1: ____

4. Prior Location: RVH 0, Home 1, Other 2: ____

5. Days on PCU prior to Interview Date: ____

6. Days from Interview Date to Death Date: ____

7. Age: ____

8. Sex: Male 0, Female 1: ____

9. Primary Malignancy: GI 0, Lung 1, Breast 2, GU 3, CNS 4, Other 5 (_____): ____

VAS PT:	Thirst:	10 ____	17 ____	Pain :	11 ____	18 ____
	Dry :	12 ____	19 ____	Nausea :	13 ____	20 ____
	Taste :	14 ____	21 ____	Fatigue:	15 ____	22 ____
	Drink :	16 ____	23 ____			

VAS RN:	Thirst:	24 ____	Pain :	25 ____
	Dry :	26 ____	Nausea :	27 ____
	Taste :	28 ____	Fatigue:	29 ____
	Drink :	30 ____		

31. Fluid Intake (0-4): ____

Laboratory:	32. Sodium	____	33. Urea	____
	34. Glucose	____	34. Osmolality	____

35. Mouth Care: (0-2): ____

36. Oral Disease: Yes 0, No 1: ____

37. Anticholinergic Meds: Yes 0, No 1: ____

38. Exclusion Reason: Confusion 0, Drowsy/Coma 1
Too weak 2, Language 3
Other 4 ____