



LAUREA
UNIVERSITY OF APPLIED SCIENCES

Prime Mover

The Edmonton Symptom Assessment Scale in cancer and palliative care pa- tients: Literature review

Ngwa, Kah Batupe

Koech, Kipchirchir Paul

2012 Otaniemi

Laurea University of Applied Sciences
Active Life Village, Otaniemi

The Edmonton Symptom Assessment Scale in cancer and palliative care patients:
literature review

Kah Batupe Ngwa
Paul Koech
Degree programme in nursing
Bachelor thesis
March, 2012

Kah Batupe & Paul Koech

The Edmonton symptom assessment scale (ESAS) in cancer and palliative care patients:
Systematic Literature review

Year	2011	Pages	30
------	------	-------	----

The ESAS is a brief and clinically useful bedside tool for self-reporting symptom intensity by advanced cancer and palliative care patients.

The purpose of this review was to get validity evidence on how the ESAS has been used as a symptom assessment tool for advanced cancer and palliative care patients. Therefore bearing this in mind, we guided our review towards finding out what the ESAS is, how the current literature review describes it and how it has been used in recent years in hospitals around the world.

The research question was: How has the ESAS been used as a symptom assessment tool for advanced cancer patients receiving palliative care?

Systematic literature review was the method of data collection with searches based on previously published studies which included articles on the ESAS, journals and internet searches. Extracted data from the literature search was done in accordance to relevance to the research task. Qualitative analysis was used. Inductive content analysis was then used to analyze the main findings of the scientific research articles.

The ESAS has been used widely in cancer and palliative care patients in some countries around the world with a great deal of success. Information obtained revealed that: the ESAS was used and compared with validated symptom assessment tools to gather validity evidence, patients were asked to think aloud while they completed the ESAS, the ESAS has been used in elderly cancer patients in different environments and settings, the ESAS has been used to give patients/families the information needed to participate in decisions about care, patients and experts agreed that the ESAS is easy to use, the ESAS was used in collecting patient symptom information for diagnostic purposes, the ESAS was used to gather/investigate patient symptom information.

However patient symptoms are a subjective experience and measurement cannot really be determined. Based on this review, directions for further validation research were also identified. In cancer and palliative care patients, pain and other symptoms can be greatly alleviated if this tool is used properly. More research however is required in the field of pain assessment alleviation.

Keywords: Edmonton symptom assessment scale (ESAS), terminal cancer, symptom assessment tool, palliative care, symptom assessment and validation studies.

Table of content

1	Introduction.....	5
2	Purpose of the study	6
3	Patients receiving palliative care.....	6
3.1	ESAS in cancer and Palliative care.....	6
4	Systematic Literature review as a method.....	8
5	Data	9
5.1	Literature search and Strategy	9
5.2	Data screening	11
5.3	Data collection and extraction.....	12
5.4	Data analysis.....	13
6	Findings.....	21
6.1	The ESAS as a symptom assessment tool	23
6.2	The ESAS was used and compared with validated symptom assessment tools to gather validity evidence.....	23
6.3	Patients were asked to think aloud while completing the ESAS.....	24
6.4	The ESAS has been used in elderly cancer patients in different environments and settings	25
6.5	The ESAS has been used to give patients/families the information needed to participate in decisions about care.....	25
6.6	Patients and experts agreed that the ESAS is easy to use.....	25
6.7	The ESAS was used in collecting patient symptom information for diagnostic purposes.....	26
6.8	The ESAS was used to gather/investigate patient symptom information.....	26
7	Discussion	27
8	Conclusion and Recommendation.....	30
	References	32
	Appendices	36
	Appendix 1 Data Analysis articles.....	36
	Appendix 2: Symptoms on the ESAS	39
	Appendix 3 The ESAS physical representation	40
	Appendix 4 The ESAS graph	41

1 Introduction

Palliative cancer patients experience a complex configuration of symptoms associated with advancing disease. These patients experience a wide array of disease and treatment related symptoms throughout the course of their illness, resulting in an ongoing need to improve both identification of these symptoms and communication about them. Symptom assessment tools have been developed to help identify burdensome symptoms and to assess the success of their management. These tools vary in clinical focus from comprehensive symptom and functional assessments to in-dept analyses of single symptoms, (Kikova et al 2006; 24:1459-1473). One tool devised and validated for rapid symptom identification and monitoring with minimal patient burden is the ESAS. According to Dennis et al. (2009, 97-102), approximately 60-80% of patients will experience pain before death. Other debilitating physical symptoms, including anorexia, nausea, amongst others occur with similar or higher frequencies, (Bradley N. et al 2005, 30:123-31).

Patients' self-reports provide the most valid measure of the experience (Kim Burchiel 2002,77-78). Adequate symptom assessment is therefore, of the utmost importance for optimal symptom management and maintenance of quality of life, which is the goal of palliative treatment and care. To address this complex symptom experience, Bruera and colleagues came up with the Edmonton Symptom Assessment System (ESAS), which is a brief and clinically useful tool for self-reporting symptom intensity by patients in advanced cancer stage. This tool was therefore, designed to enable repeated quantitative measurements of symptom intensity with minimal patient burden. It includes nine common symptoms of advanced cancer (pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, wellbeing, shortness of breath), with the option of adding a 10th, patient-specific symptom. Since its inception in 1991, the ESAS has been adopted by palliative care programs nationally, across Canada, and internationally across Europe and Asia, for clinical, administrative and research purposes.

This study was mainly aimed at introducing the Edmonton symptom assessment scale into the Triangle Hospital which is a specialized hospital for internal medicine. The main goal was to concentrate the practice of all medical procedures and special care services in one building. This study aims at benefiting the future hospital and its staff with information about the ESAS and how it can be used with cancer and palliative patients. These studies were conducted thanks to the collaboration between Laurea and the Triangle Hospital.

2 Purpose of the study

The purpose of this review was to get validity evidence on how the ESAS has been used as a symptom assessment tool for advanced cancer and palliative care patients.

Research question: How has the ESAS been used as a symptom assessment tool for advanced cancer and palliative care patients? The research question enabled us to narrow our literature search and it was of much help in data collection.

3 Patients receiving palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 1998a). WHO recommends that palliative care be offered at the beginning of any life-limiting condition at the same time as curative efforts, recognizing that the transition to purely palliative or hospice care may later occur.

Palliative care encompasses the whole self, caring for the physical, emotional, and spiritual needs of patients and their families. It provides relief from pain and other symptoms of illness such as fatigue, nausea, shortness of breath, and loss of appetite. Angela Morrow, Rn (2011) states that, "the patient can get on with daily life". It is important for nurses who care for the dying to be aware of their own feelings about death and about their patients. It is difficult to see people die who you have cared for. It is especially difficult if a child or young person dies. The nurse has not only cared for them, he/she has also cared about them. Many nurses feel frustration and grief when their patients die. It is important to recognize those feelings. Comfort and support for each other in care of the dying is very necessary.

3.1 ESAS in cancer and Palliative care

Most articles on different studies have shown that lack of systematic symptom assessment is one of the reasons for sub-optimal symptom management. Due to the fact that symptoms are subjective by nature, it is generally agreed that the patient is the most valuable source of

information. The ESAS is a widely used and well-known self-reporting tool for assessment of symptoms in palliative care. ESAS as a tool is easy and expedient to use and can be used for day-to-day monitoring of treatment effect and change in symptoms, all of which are important factors in advanced cancer. Despite the extensive use and validation of the ESAS, recent research has questioned how well it works as a self-reporting tool in palliative care. Symptoms such as: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, shortness of breath, are all typical to cancer and palliative patients. The ESAS is a valid and reliable assessment tool to assist in the assessment of these symptoms, thus the reason why the original tool was developed by the Regional Palliative Care program, Capital Health in Edmonton, Alberta. (ML Slevin et al. 2006, 1275-1277).

The ESAS was designed so that the patient, or his/her family caregiver, could self-administer the tool. Therefore, the patient should be taught how to complete the scale. It is the patient's opinion of the severity of the symptoms that is the "gold standard" for symptom assessment, (Moro C et al 2006, 30-37).

The ESAS provides a clinical profile of symptom severity over time. It provides a context within which symptoms can be understood. However, it is not a complete assessment in itself. Reese et al. (1998), states that, "for good symptom management to be attained, the ESAS must be used as one part of a holistic clinical assessment," (Reese et al.1998, 75-82).

Ideally, patients fill out their own ESAS, however, if the patient is cognitively impaired or for other reasons cannot independently do the ESAS, then it is usually completed with assistance by the caregiver or a health professional closely involved with the patient's care. If the patient cannot participate in the symptom assessment, the ESAS is completed by the caregiver or healthcare professional. When the caregiver or professional completes the ESAS alone the subjective symptom scales are not done, that is; tiredness, depression, anxiety, and well-being are left blank and the caregiver assesses the remaining symptoms as objectively as possible, that is, pain is assessed on the basis of a knowledge of pain behaviors, appetite is interpreted as the absence or presence of eating, nausea as the absence or presence of retching or vomiting, and shortness of breath as labored or accelerated respirations that appears to be causing distress for the patient, (Philip et al 1998,539-41).

4 Systematic Literature review as a method

Referring to Tranfield, Denyer and Smart, 2003, 207-222, a systematic literature review is a broad review of a field of study to assess the relevance and size of the literature and to delimit the subject area or topic. Such studies need to consider cross-disciplinary perspectives and alternative ways in which a research topic has previously been tackled. The scoping study may also include a brief overview of the theoretical, practical, and methodological history debates surrounding the field and subfields of study. Literature review method is designed to reduce any unintended bias, which may occur if other methods were used as literature review is systematic and each step of the research is noted and accounted for, (Tranfield et al 2003).

As reported by Poulson and Wallace,(2004), literature review is a reviewer's critical account designed to convince a particular audience about what published (and possibly also unpublished) theory, research, practice or policy texts indicate and what is not known about one or more questions framed by the reviewer, Poulson and Wallace,2004,25-30.

A literature review is an account of what has been published on a topic by accredited scholars and researchers. A literature review is a body of text that aims to review the critical points of current knowledge including substantive findings as well as theoretical and methodological contributions to a particular topic. Literature reviews are secondary sources, and as such, do not report any new or original experimental work, Dellinger,A, 2005,41-54.

Systematic literature review was chosen in order to extract important information from already available material and important concepts and theories related to our study.

For this study and in order to minimize bias, the principles of conducting a systematic review was done by using clear objectives and a comprehensive search strategy and explicit inclusion and exclusion criteria were applied. There are no standardized assessments for evaluating the quality of validation studies in instrument development, thus for the purpose of this thesis, the measurement principles of reliability as outlined by Crocker and Algina (2006, 88-90) was applied. A framework for gathering validity evidence proposed by (Messick et al 2009, 164-5) was also of significant help.

5 Data

Articles identified through the search strategy were retrieved by Literature search. Screening, data extraction and data analysis were steps applied in the process of collecting data. The study is a literature review based on relevant scientific research articles, journals and text books.

Key concepts: Edmonton symptom assessment scale (ESAS), terminal cancer, symptom assessment tool, palliative care, symptom assessment and validation studies were used.

5.1 Literature search and Strategy

The systematic and explicit search of published materials relevant to the study is referred to as literature search. Identifying articles, journals, research reports and information relating to the ESAS was the first stages in the literature search. Making use of electronic databases and internet search engines helped in identifying relevant sources. Previous knowledge also played a part and several search engines were also used to obtain various results.

The articles evaluated in this report were identified through a comprehensive search of electronic databases such as: Science Direct, Healthline, Medline, Webd, HealthFinder, Pubmed, Wmarse(Electronic Medical Record Search Engine), Healthstar and Biomed using the keywords: ESAS(Edmonton Symptom Assessment Scale), terminal cancer, Palliative care, symptom assessment tool, symptom assessment and validation studies. The keywords were typed into an advanced keyword search where necessary. For the relevant articles, reference list was reviewed where necessary. Potential sources were identified.

Table 1: Electronic Engines Searched

Data Search engines	Potential sources	Non-potential source	Sources in English	Sources non in English	Sources under construction	incomplete sources
Science Direct	X		X			X
Healthline		X		X		X
Medline	X			X		X
WebMd	X		X			X
HealthFinder	X		X			X
PubMed	X			X	X	
EMERSE(The Electronic Medical Record Search Engine)	X		X			X
Healthstar	X		X			X
Bio med	X		X			X

In table1, An X is used to indicate search engines that provided potential pertinent sources, non-potential pertinent sources, sources not in English, incomplete sources and sources under construction. Essentially, while proceeding with the literature search, the keyword list was redefined to include words that produced relevant results so as to locate sound evidence on the research study. We had to join keywords so as to narrow down results (table 2.). Literature review was retrieved mainly from search engines containing medical and scientific journals.

Table 2: Search words used and hits or results obtained from various search engines.

Searched words	Science Direct	Health-line	Med-line	WebM d	Health-Finder	Pub-Med	EMERSE(The Electronic Medical Record Search Engine)	Health star	Bio med
Edmonton Symptom Assessment System(ESAS) and Palliative Care	139,552	0	55	0	0	55	43	4	0
symptom assessment tool	1,725	55	17720	115	0	724	7920	1	1480
symptom assessment and validation studies	331	55	0	331	0	534	545	0	0

5.2 Data screening

Research articles with a primary focus on gathering reliability and validity evidence for the ESAS; published in peer review and English language; year of publication from 2000 to 2011 were included in this review, however some older articles were also referred to, given the fact that the ESAS was inceptioned in 1991.

Exclusion criteria included review articles published in languages other than English, research abstracts, for example poster and oral conference presentation abstracts and research studies which included the ESAS but did not have key focus on ESAS validation/reliability and incongruence with the research question or insufficient quality.

Table 3: Inclusion/exclusion criteria

INCLUSION	EXCLUSION
Studies in English language	Studies not in English Language
Studies related to ESAS	Studies not related to ESAS
Studies based on validity evidence and empirical research	Studied not based on validity evidence and empirical research
Publications from 2000 till 2011	Studies published before year 2000
Well defined study purpose and relevant outcomes	Not well defined study purpose and irrelevant outcomes
Complete articles	imcomplete articles(posters/abstracts)

5.3 Data collection and extraction

Data extraction is the act or process of retrieving data which complies with the review after assessment of different sources for further data processing or data storage (Ralph Kimball, 2008). Data extraction was used to draw out key themes in the evidence as part of the synthesis stage of the review process. The purpose statement and research questions guided in ensuring that the data chosen was correct. Relevant articles in relation to the study were listed and discussed. The articles identified through the search strategy were retrieved and summarized in a database using the following categories: publication date, authors(s), population/sample, study design, types of tools used, study purpose and relevant outcomes, see appendix 1(Data analysis articles). The purpose statement and research question helped in the extraction of data. Articles were screened independently by reviewing the title and abstract of each article as well as the database summary. A list of potential articles for in depth review was created based on inclusion criteria.

5.4 Data analysis

Qualitative analysis means making sense of relevant data gathered from various data sources, then responsibly presenting what the data reveals. Often the journey from raw data to what the data reveals is challenging. Analysis finally makes clear what would have been most important to study, if only we had known beforehand, (Patton; 2002, 43). In this review, the main findings of the scientific research articles were analyzed using inductive content analysis. Inductive analysis is immersion in the details and specifics of the data to discover important patterns, themes and interrelationships. "Content analysis is a research technique which can be used for objective systematic and qualitative description of documentary evidence". Proper grouping of findings into suitable categories came as a result of proper familiarization with the data, (Johnson & Christensen (2004). Biondo-Wood & Haber, 2006.559-575)

The analysis of this study was carried out in the following phases: becoming familiar with the data set, systematizing the data, looking for themes, reviewing the topic again, defining and naming the theme, creating the report. The selected articles were read through thoroughly and their contents were related to the research task with guidance of the research question and the purpose statement. Relevant information to the research study was noted down and a table of summary with a short description of the various articles was made.

The analysis process included sorting, which means we had to decide on what is more important and less important in the data in relevance to the research question. The process also included inductive coding, which according to Thomas (2003), begins with close reading of the text and consideration of multiple meanings that are inherent in the text. Text segments were then identified and a label was created for a new category.

Picking similar content and grouping them together was the second step, forming the first category. The grouped categories were given titles that best describe them. For example, the articles talked about gathering ESAS evidence by comparing it with different symptom assessment tools, both disease and symptom specific e.g. RSC (Rotterdam symptom checklist) and prove of ESAS correlation with the compared instruments. These were grouped together to form the first main category which answered the research question. ESAS was used and compared with validated symptom assessment tools to gather validity evidence.

The most important task in analysing data is to be fully knowledgeable with the raw data that is to be analysed. The best way in doing so is by reading the raw data several times in order to develop various categories from the data into a model of framework so as to identify key themes (Thomas 2003). The chosen articles were systematically read repeatedly in order to establish its relevance to the research task. Important concepts were colour coded while going through the articles for easy identification during categorization.

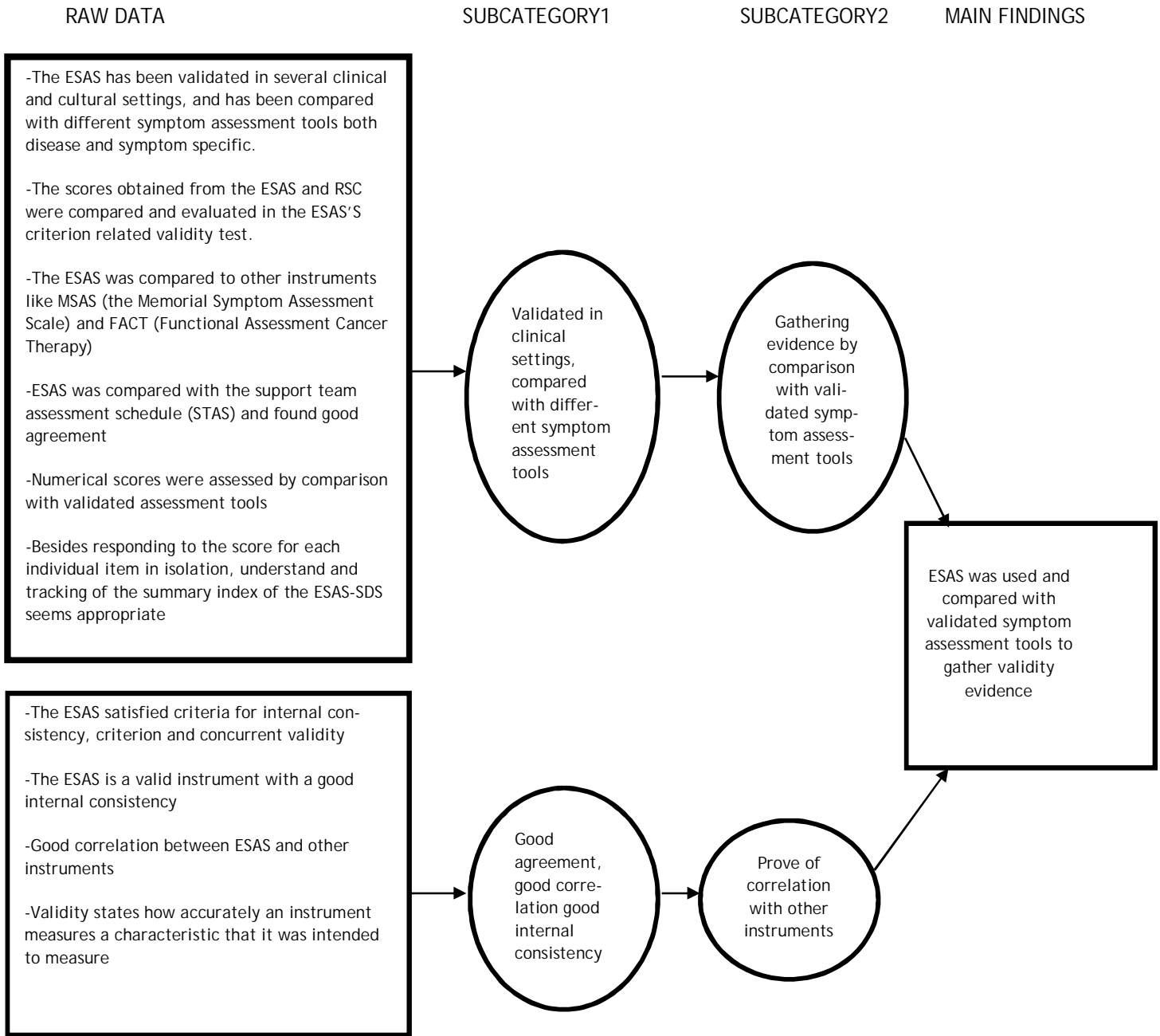


Figure 1. Analysis illustration of ESAS and comparison with validated symptom assessment tools to gather validity evidence.

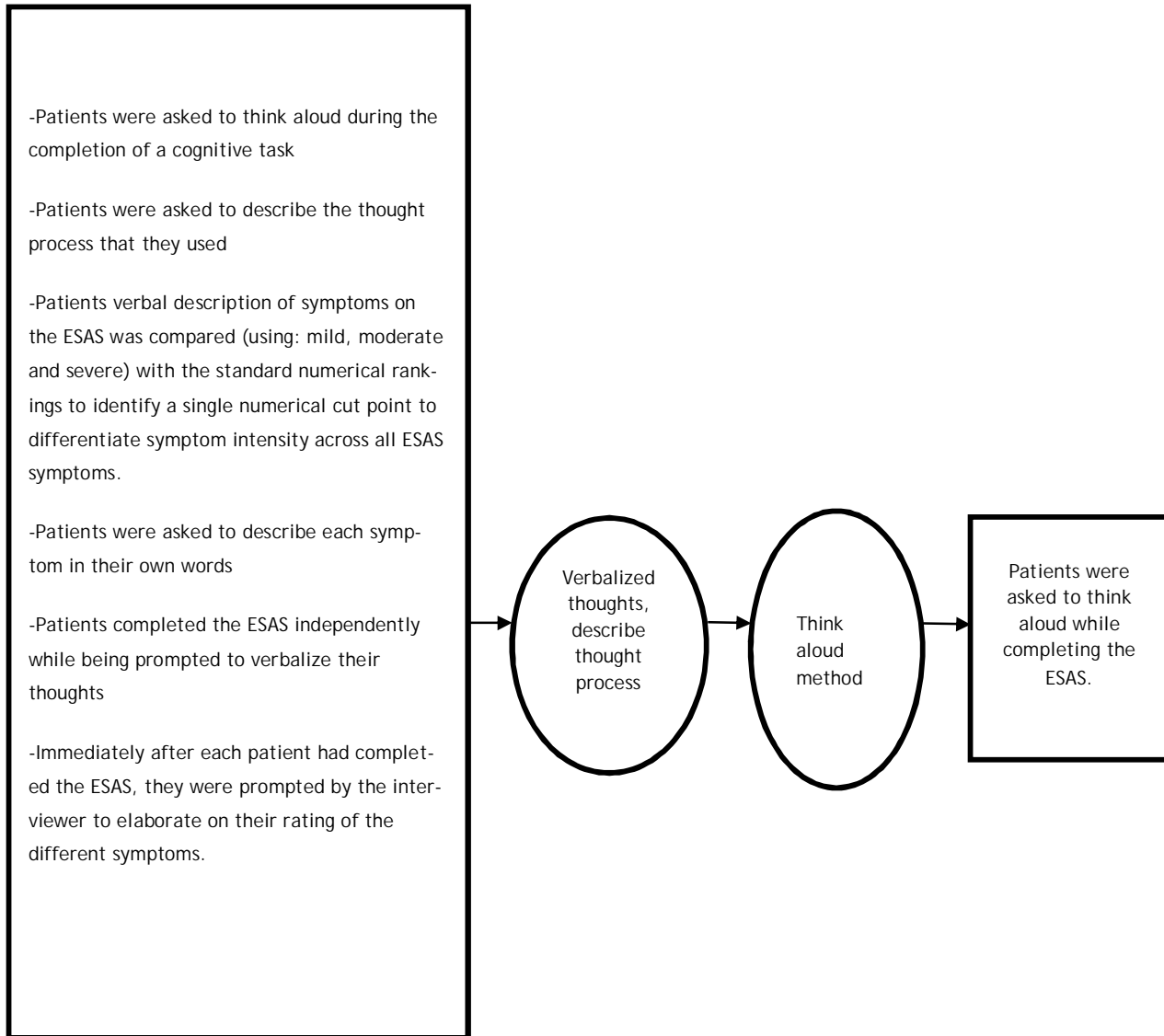


Figure 2. An analysis illustration of how the expert (interviewer) engaged his patient to get their verbal description of symptoms on the ESAS

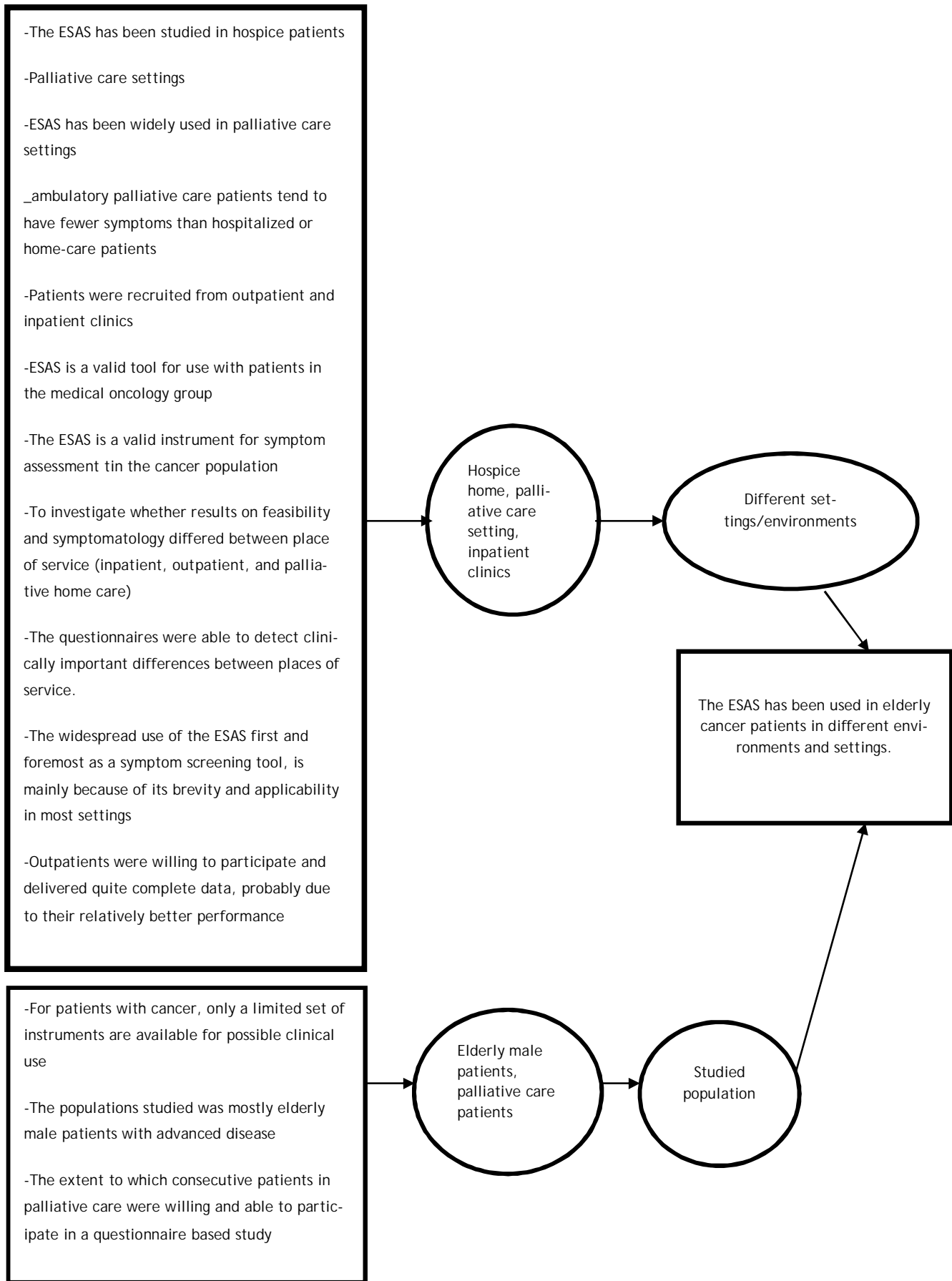


Figure 3. An analysis illustration on the use of ESAS in different settings and environments.

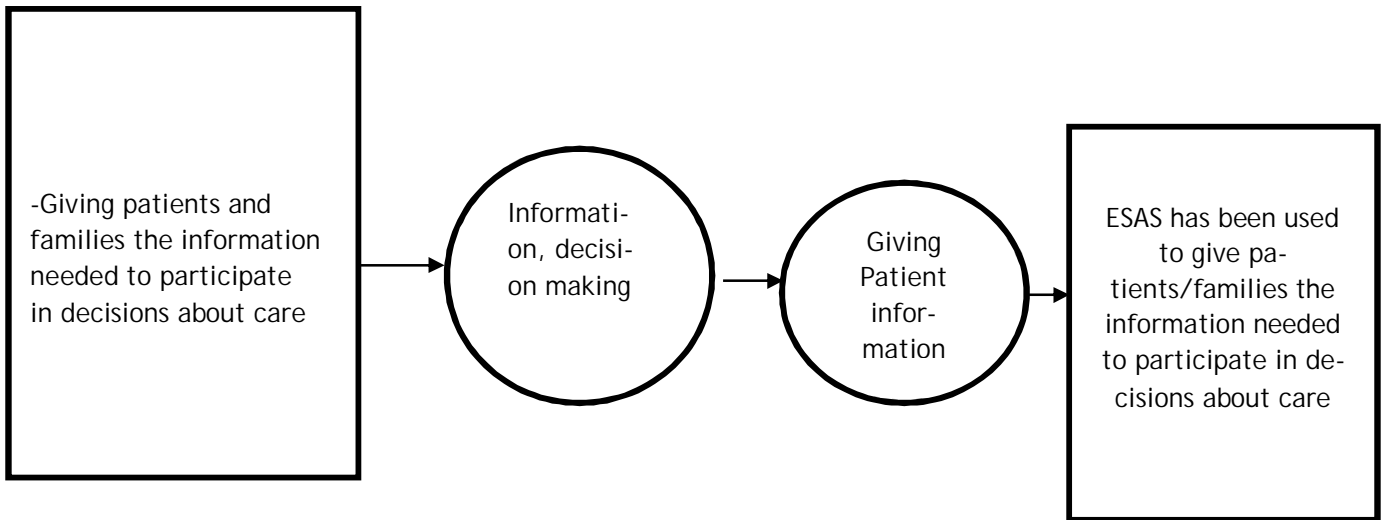


Figure 4. An analysis illustration showing ESAS use to involve patient and their families to participate decisions about care.

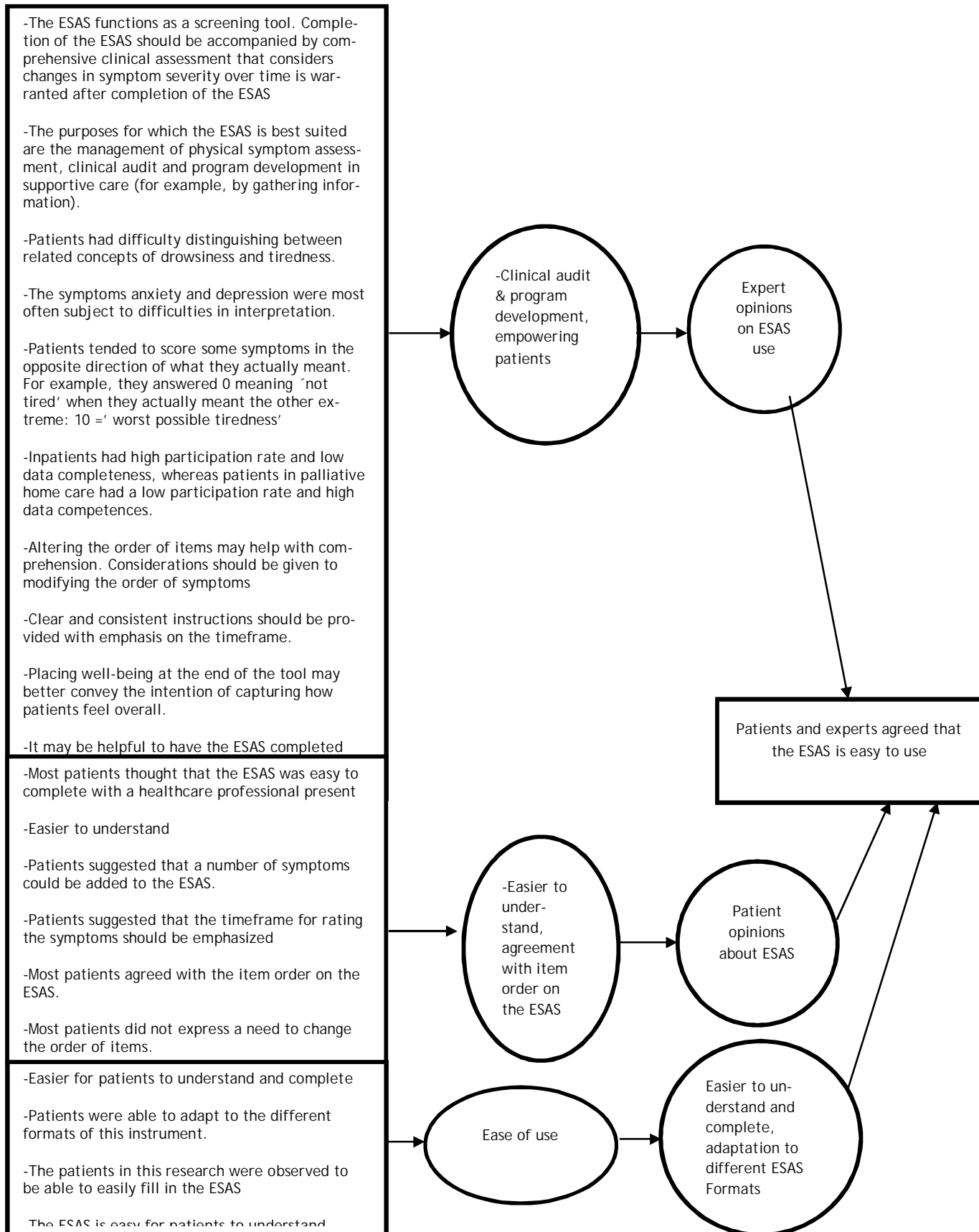
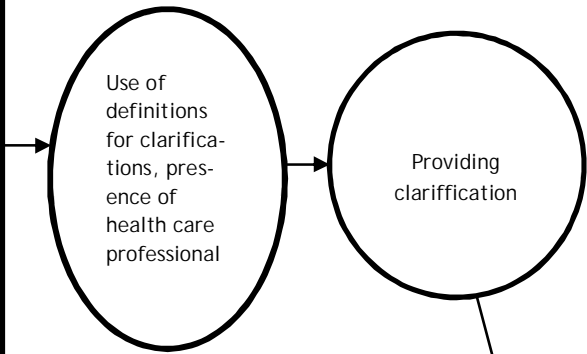
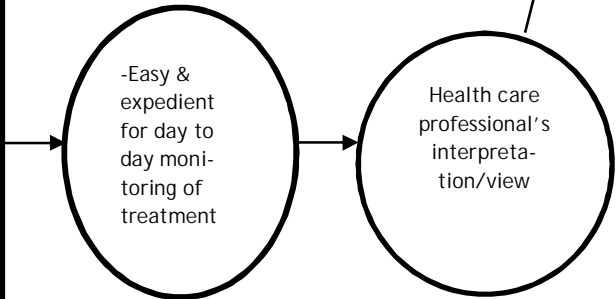


Figure 5. An analysis illustration of ESAS as an easy to use tool in cancer and palliative care.

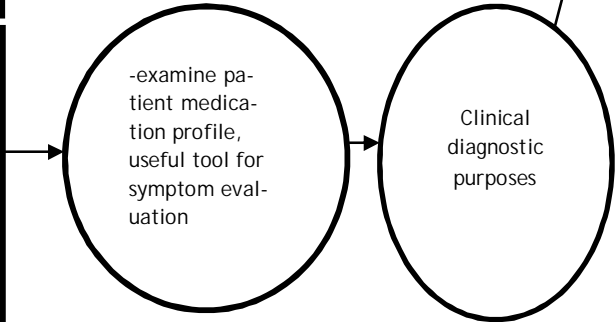
- Nurses may need to give more explanation to patients in the use of the ESAS, because patients are able to adjust to the differences in these types of tools
- Health care professional is available to provide clarification
- Sit down and carefully go through the completed form together with the patient
- Definitions were used for clarification
- A script was used to ensure consistency of instructions across patients
- Optimal definitions and time frames for symptoms assessments
- All consenting patients independently completed the ESAS in the presence of the research nurse or assistant
- The inclusion of definitions would be helpful to assist with interpretation of potentially confusing terms.



- The tool is easy and expedient to use and can be used for day-to-day monitoring of treatment effect and change in symptoms all of which are important factors in advanced cancer.
- Forming a judgment, and editing the answers (self-reporting)
- The patient provide the most valuable source of information
- Patients and health care professionals interpretations of item scales
- Patient perceptions, interpretations, desires and expectations must be understood
- Implementation requires interpreting the ESAS and having acceptable responses to the information it provides
- The ESAS was modified to suit patient needs and for use
- ESAS has received much interest as a bedside clinical instrument
- After each interview, the research nurse or assistant completed a field note summary
- Cognitive interviewing was conducted while the respondent is filling in the questionnaire
- The research nurse or assistant administered a structured questionnaire to elicit patient opinions of the ESAS
- A standardized method for using the ESAS is a prerequi-



- Examine patients' medication profile
- Useful tool to nurses to use in the evaluation of their patient symptoms
- Finally, self-assessment questionnaires also may be used clinically for diagnostic purposes.
- The results may be used to assess and compare the symptomatology and treatment effects within a department and between institutions
- Coordination of care, including arranging for expert help and services in the community.



The ESAS was used in Collecting patient symptom information for diagnostic purposes

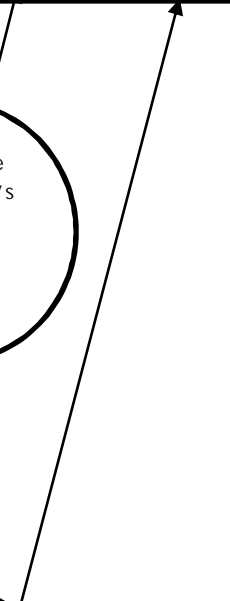


Figure 6 above. Shows an analysis illustration detailing ESAS use for diagnostic purposes.

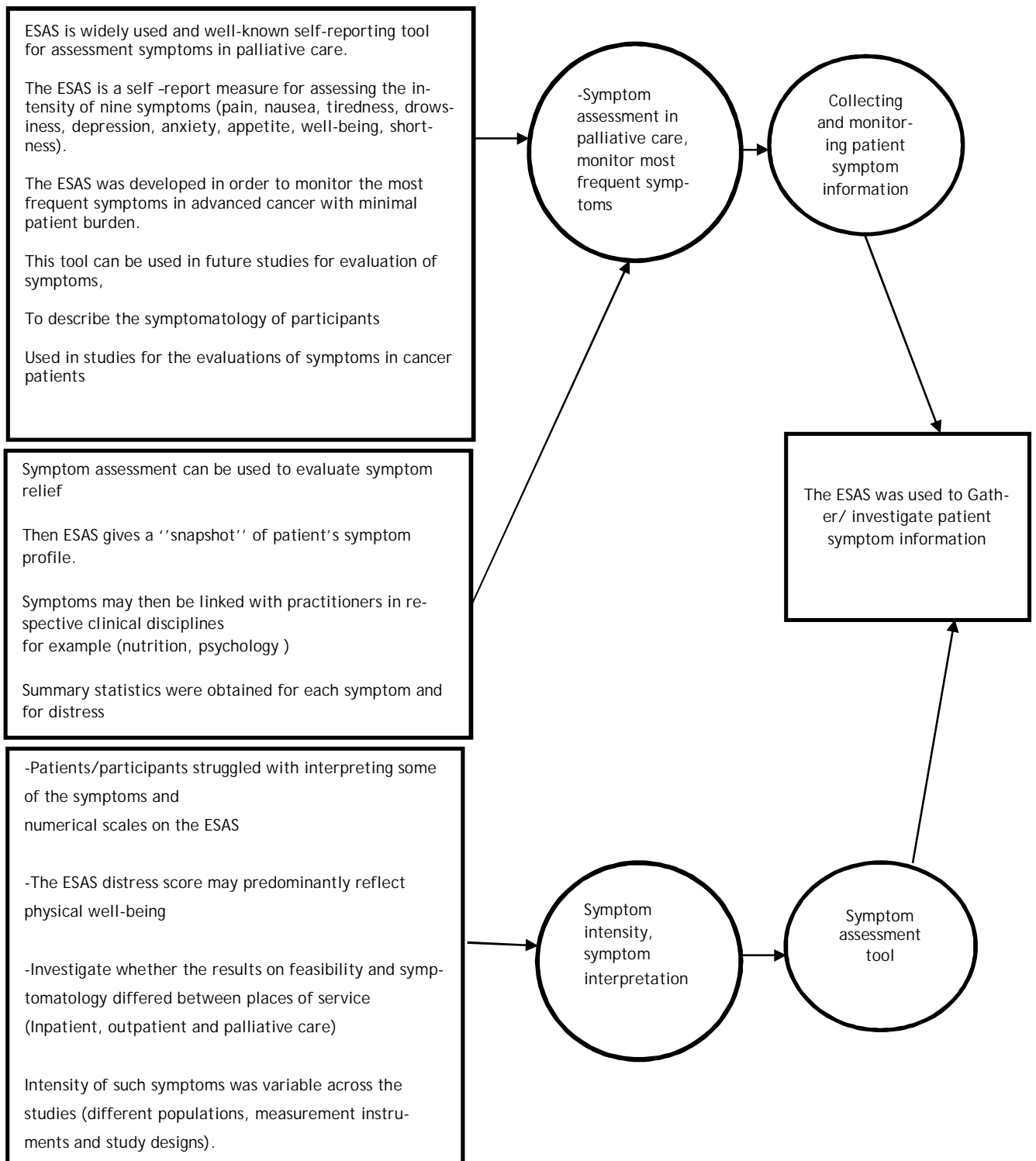


Figure 7. An analysis illustration showing ESAS use in investigating patient symptom information.

6 Findings

Upon completion of the analysis process, the final result that emerged from the data was then examined to make sure it was congruent with the purpose of this study and that it answered the research question. The following themes were identified at the end of the analysis: ESAS was used and compared with validated symptom assessment tools to gather validity evidence, patients were asked to think aloud while completing the ESAS, the ESAS has been used in elderly cancer patients in different environments and settings, ESAS has been used to give patients/families the information needed to participate in decisions about care, patients and experts agreed that the ESAS is easy to use, the ESAS was used in collecting patient symptom information for diagnostic purposes, the ESAS was used to gather/investigate patient symptom information.

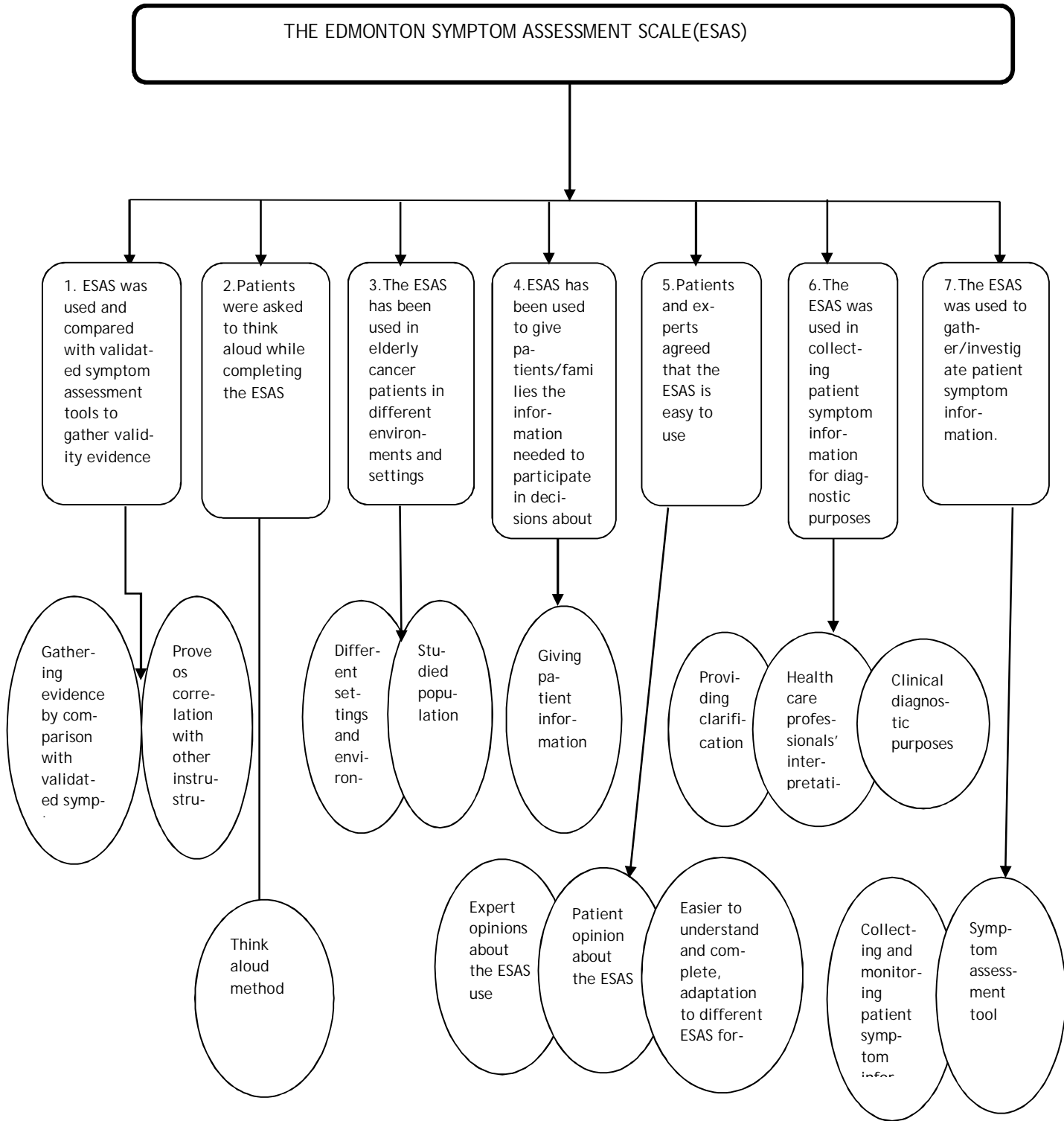


Figure 8: An illustration of main categories and subcategories.

6.1 The ESAS as a symptom assessment tool

Palliative and patients with advanced cancer are most often polysymptomatic (Chiu TY et al 2000; 8:311-3). The ESAS is a nine-item patient rated symptom visual analogue scale developed for use in assessing the symptoms of patients receiving palliative care. Palliative care and cancer patients experience a wide array of disease and treatment related symptoms throughout the course of their illness, resulting in an ongoing need to improve both the identification of these symptoms and communication about them. Symptom assessment tools have been developed to help identify burdensome symptoms and to assess the success of their management. These tools vary in clinical focus from comprehensive symptom and functional assessments to in-depth analyses of single symptoms. The ESAS was devised and validated for rapid symptom identification and monitoring with minimal patient burden.

6.2 The ESAS was used and compared with validated symptom assessment tools to gather validity evidence

Whenever a measuring device is used as part of data collection process, the validity and reliability of that instrument is important. Concurrent validity refers to a measurement/assessment devices' ability to vary directly with a measure of the same construct or indirectly with a measure of an opposite construct. It allows the researcher to show that the tool under investigation is valid by comparing it with an already valid tool. Comparing the ESAS with validated symptom assessment tools was one way to prove its' validity for use in cancer and palliative care.

Validity is the most important issue in the evaluation of an instrument of measurement. Validity states how accurately an instrument measures a characteristic that it was intended to measure. Validity can be proven in three ways with content validity, criterion-related validity, and construct validity (Can G,2004;27:153-61).

A range of self-assessment questionnaires evaluating physical symptoms and psychosocial and cognitive functions is available. Burera and Macdonald compared the ESAS with the Support Team Assessment Schedule (STAS) and found good agreement. Philip et al compared the ESAS with the Rotterdam symptom checklist (RSCL) and the Brief Pain Inventory validates for the Australian population and found a good correlation. Rees et al found practical difficulties in assessing 71 patients admitted to a British hospice, showing that patients with a very low performance status need other tools for symptom assessment. Dudgeon et al used ESAS to audit the adequacy and speed in symptom control in a Canadian palliative care hospital. Chang et al demonstrated the good agreement between the ESAS, the Functional Assessment Cancer Therapy(FACT), the Memorial Symptom Assessment scale(MSAS) and the Karnofsky Performance Status(KPS), showing that the ESAS is a valid instrument with good internal consistency. Heedman et al. used ESAS for symptom assessment in home care cancer patients. Finally Stromgen et al used ESAS, the European organisatin for Research and Treatment of Cancer Quality of Life Instrument (EORTCQLQ-30) and the Hospital Anxiety and Depression scale (HADS) for assessing symptoms in three palliative care settings: in-patients, outpatients and home care patients.

6.3 Patients were asked to think aloud while completing the ESAS

As part of gathering validity evidence for the ESAS, a study focused on exploring patients' cognitive processes while completing the ESAS, patients' understanding of ESAS terminology and numerical ratings of symptom intensity and eliciting patients' opinions on the ESAS terminology. Using a qualitative "think aloud" study design, patients completed the ESAS independently while being prompted to verbalize their thoughts. They answered a structured questionnaire to elicit their opinion of the ESAS. The verbal reports were then transcribed and analyzed using qualitative approaches such as discourse analysis (Chow E et al, 200253:1291-302). This method was used as a result of the concern that errors may occur in patient self-assessment of symptom intensity suing the ESAS as a result of of the patients interpreting and completing the ESAS differently from what it was intended and If so, health care providers may misunderstand their patients' symptom experiences, possibly resulting in suboptimal symptom management (Sharon Watanabe et al 2008). The use of the think aloud enhances the understanding of the cognitive processes that patients use to complete the ESAS and identifies potential sources for misinterpretation and error. This approach is appropriate for understanding potential cultural differences in symptom assessment, using the ESAS.

6.4 The ESAS has been used in elderly cancer patients in different environments and settings

A series of validation studies have complemented the rapid clinical uptake of the ESAS, providing further evidence for its psychometric properties and clinical utility (Nekolaichuc c et al, 2008; 22:111-122). The ESAS is a widely used self-reporting symptom intensity tool for assessing symptoms in palliative care and has undergone widespread adoption in palliative care programs nationally and internationally, for clinical research and administrative purposes (Heedman PA,2001;21:4077-4082), (Öznur Usta et al 2008)

6.5 The ESAS has been used to give patients/families the information needed to participate in decisions about care

Patient information is important as it can help patients, family and the medical staff involve in treatment and condition. Patient information ensures patients/family are fully aware of the next step in their pathway and are able to plan ahead. This information allows room to identify any developments or abnormalities in patient history. The ESAS provides symptom information profile. When patients self-report their symptoms, the prevalence and severity data for the symptoms tend to vary significantly from those identified by health care providers and from the data recorded in charts and research forms (Davidson et al 2007;69:1218-21) . Patients may be better able to identify and assess symptoms that have a larger subjective component, for example, pain or fatigue. Discrepancies in clinical priorities and symptom subjectivity may explain the dissatisfaction with physical care registered. (LA Richardson et al, 2007).

6.6 Patients and experts agreed that the ESAS is easy to use

Validation studies pointed out the fact that concepts in a symptom assessment tool may be difficult to understand and that patients may confuse or misunderstand certain concepts. Therefore a study focused on gathering ESAS validity evidence by exploring the potential difficulties that advanced cancer patients may have in interpreting and completing this tool. Multicenter studies conducted in a variety of palliative care settings patients' perceived ease of understanding and completion of the ESAS (Sharon M. Watanabe et al 2011). The ESAS provides the option of adding a 10th specific symptom which gives the patient the opportunity to mention if there is anything else apart from the symptoms items for which the ESAS was intended. The overall design of the ESAS is that, the internal structure as well as the external structure. Brevity and ease of administration has made ESAS a preferred bedside clinical instrument.

6.7 The ESAS was used in collecting patient symptom information for diagnostic purposes

The ESAS was designed to enable repeated quantitative measurements of symptom intensity with minimal patient burden. Detection and treatment of symptoms are major targets of palliative care. Therefore a thorough mapping of symptoms and problems in patients is essential to acquire knowledge of symptom variety and severity. The ESAS gives a "snap shot" symptom profile, however collected symptom information however requires a sound clinical process to help interpret scores and to give them an appropriate level of attention (Bruera E et al 1991;7:6-9). Adequate symptom assessment is the utmost importance for optimal symptom management and maintenance of quality of life, which are the goals of palliative treatment and care (WHO, 2010).

6.8 The ESAS was used to gather/investigate patient symptom information

The results of questionnaire-based studies can be used to describe the characteristics of patients in palliative care and to evaluate the effect of palliative care. The results may be used to assess and compare the symptomatology and treatment effects within a department and between institutions. Finally self-assessment questionnaires also may be used clinically for diagnostic purposes (Detmar SB et al 1999; 17:998-1007).

7 Discussion

“Symptom assessment is a key priority of palliative care,” (McDowell J and Clark R. 2007, 14,175-188). The ESAS was first described as far as we know in a group of palliative care patients in a hospice setting. Brevity and ease of administration has made ESAS a preferred bedside clinical instrument. In a review of QOL tools for patients with cancer, proposed criteria for an ideal instrument included one that would be simple to read and follow and quick and easy to complete and analyze and be based on a categorical or visual analogue scale(Dudgeon et al 2006,465-47). The ESAS, as we found out, has many of these features and measures as many important symptoms of interest.

In this thesis, we have evaluated the ESAS validation for non-hospice patients with a diagnosis of cancer as examined in a hospital setting. The ESAS satisfied criteria for internal consistency, and concurrent validity. We found that responses to the ESAS showed much approvals from the different hospitals where it has been used. One main thing is that the instrument is sensitive to fluctuations of the patient’s symptom status, or that, patients’ perceptions of symptoms may change as well, or that weekly repetition may miss significant changes, (Chang VT et al, 1995, 14-16). Whether this is an advantage or disadvantage depends upon the purpose of the user. There may be a compromise between stability and sensitivity because the requirements for evaluation functions of an instrument may differ.

Little is known about the ideal interval for reassessment. Our sample is very small, and more research with longitudinal follow-up is required to better define the ideal frequency of assessment. Further insight into the meaning of the ESAS scores is provided by the correlation coefficients of ESAS scores with summary scores of other instruments. One reason may be that the ESAS instrument has six items related to physical well-being, and three related to psychological symptoms (Periyakoil VJ, Hallenback J 2002, 883-890). The meaning of specific symptom assessments also can be approached by such analyses. One particular symptom of interest is pain. In this study, these results also confirm the correspondence of pain ratings with the worst pain severity. This tendency may be part of a larger phenomenon whereby patients may remember extremes rather than average aspects of an experience; a related issue is assessment of pain severity (Moro C et al 2006, 30-7).

ESAS results suggest that for pain in patients, there is very much distress. We have explored this idea further in three other prevalent symptoms in the categories of severity and distress. Such a cutoff would be very useful for the physical symptom shortness of breath for both severity and distress dimensions, and for severity alone in ESAS psychological items such as anxiousness and drowsiness. One cutoff value may not be appropriate for all symptoms, and further work is needed. Of interest is the observation that symptom prevalence as measured by the ESAS is higher than in other scales. This raises the issue of how surveys with different

instruments can affect prevalence and suggests a potential variation of up to ten percent. (Kimberly B. Chapman, 2009, 21-25).

Wording of psychological symptoms may affect measures of prevalence, as illustrated by differing responses to "feeling sad" or "depression" and "feeling nervous" or "anxiety." Another possibility is

Wording of psychological symptoms may affect measures of prevalence, as illustrated by differing responses to "feeling sad" or "depression" and "feeling nervous" or "anxiety." Another possibility is that some symptoms may be so distressing that patients recall them on the ESAS even though they may not have experienced them within given period of time.

There are a number of limitations on the studies focusing on the ESAS. The patients studied in most of the researches were mostly elderly male patients with advanced disease. Other populations, such as patients with early disease and female patients, still need to be studied further. What about severely ill and older patients with shaky hands and poor eyesight who may experience difficulty in understanding and completing the ESAS?. For these patients, a numeric rating version may be helpful as results from numeric rating scales have been shown to be similar to visual analogue scales for pain and for quality of life (Anne F. Mannion, 2007, 610-618).

This study was not meant to compare ways of presenting information from the ESAS (a graphic display) with information. The relative value of graphic versus numeric reporting should be addressed in future studies. The services of the school librarian were of great help as well as previous knowledge.

Findings outlined the fact that; selection of appropriate assessment tools should consider developmental levels rather than simply an age appropriate tool. Attempts have been made to validate instruments to assess pain in cancer and palliative care patients, but there is not yet consensus on a standard procedure for assessing pain. Nurses and physicians should collaboratively attempt individualized systematic assessment and intervention, taking into consideration the fact that, in assessing pain in patients who are not able to provide their own report (Pasero 2000,22-23), a condition or procedure that is likely to cause pain in a cognitively intact patient is likely to cause similar amount of pain in a cognitively impaired, comatose, sedated, immobilized or demented person (Shannon K T 2003,154-162) and (Puntillo et al 2002,303-314).

Physiological measures are nonspecific indicators of stress or distress, they are useful surrogate indicators for acute pain (but not persistent pain) when they are used in conjunction with other observations. Our findings also showed that, behavioural signs are useful surrogate indicators for acute pain and sometimes for persistent pain, however they should be monitored and documented systematically and whenever possible, a tool validated in the patient's population should be used (Herr K 2006, 170-192).

Articles also outlined the fact that, family members may be able to provide valuable insight into the behaviors that may be associated with pain especially in children. In addition, neuromuscular blockade may prevent behaviors that are indicative of pain, but does so without providing analgesia and also sedation may prevent behaviors that are indicative of pain, but usually does so without providing analgesia. This, thereby supports the fact that an analgesic trial can be both diagnostic and therapeutic (Villanueva 2003,1-8).

Moreover findings showed that creativity and sensitivity to individual patient needs facilitates pain assessment and management in cancer and palliative care patients. In cancer and palliative patient, consistent, collaborative, systematic assessment is the key to adequate pain management in all populations, (Warden et al 2003,9-15).

Some patients are unable to provide a self-report or may be impaired by disease or treatments; as such they are at high risk for unrecognized pain. It may be helpful to consider the commonly used pain assessment instruments to see if an instrument appropriate to the patient's developmental stage or conditions is available. Communication between nurses and other clinical specialists may help in identifying pain indicators (Young J et al 2006, 32-9).

More so, if a patient reports pain prior to becoming unresponsive, assume that the painful conditions persists unless there is reason to believe otherwise and pain indicators should be documented so that colleagues may share a consistent method of assessment (Pasero 2002,59-60).

8 Conclusion and Recommendation

The ESAS has been used successfully and extensively as a measurement tool in palliative care services in that, it is simple, short and self-completed, avoiding physician and nurse bias. The respondent burden is low, and the instrument was completed readily by subjects in this study, even among those close to death. It can also be administered repeatedly. Prior to this study, no comparisons between the ESAS instrument and other self-administered symptom assessment tools have been reported.

This study demonstrates that the modified ESAS has satisfactory concurrent validity, compared with the Brief Pain Inventory and the Rotterdam symptom check list, for patients with incurable cancer. The components of validity include face validity, construct validity, criterion validity and repeatability.

We have assessed concurrent validity in this study, as there is no gold standard (criterion) against which to measure this instrument; the face validity is undisputed and according to the data used, all subjects instantly recognized the intent of the questionnaire, and the construct validity appeared to be acceptable to palliative care practitioners.

Repeatability cannot be adequately assessed in palliative care populations, because of the patients' unstable symptoms. We conclude that the modified ESAS is a valid, short, self-administered instrument for assessment of pain and other symptoms in cancer patients in differing palliative care settings. Palliative care and its proximity to end-of-life care issues frequently raise ethical issues for patients, their families, and the clinicians caring for them (Donna L. Berry 2005, 63-68). Supporting the identification and honoring the patients' preferences for treatment are central components of ethical behavior.

This thesis alongside other previously published materials agrees with the fact that most of the reliability and validity evidence on the ESAS has been focused on test-retest reliability and concurrent validity.

Recommending further studies, more research could be carried out in finding out the appropriate responsiveness of the ESAS to the treatment interventions, potential differences across different populations for instance Africa, different versions of the ESAS for example English and non-English version. Recommendations for further studies for example validating the use of the ESAS in cancer patients earlier in the cancer trajectory, in different settings other than inpatients and in non-cancer populations could be of great help. Gathering further validity evidence for the ESAS will strengthen the credibility of its use as one of the potential standard assessment tools for pain and symptom assessment in research and clinical practice.

Recommendations for further studies include for example validating the use of the ESAS in cancer patients earlier in the cancer trajectory, in different settings other than inpatients and in non- cancer populations could be of great help.

References

- Abernethy, Amy, P. 2006: Patient self-reporting in palliative care using information technology, 1059-65.
- Angela Morrow, Rn 2011: Recognizing the Dying Process, 24-26
- Anne, Mannion F., 2007 : Pain measurement in cancer patients,610-618.
- Bradley N, Davis L, Chow E. Symptom distress in patients attending an outpatient palliative radiotherapy clinic. *J Pain Symptom Manage* 2005; 30:123-31.
- Brandt HE, Ooms ME, Deliens L, Van der Wal G, Ribbe MW. The last two days of life of nursing home patients-a nationwide study on causes of death and burdensome symptoms in The Netherlands. *Palliat Med* 2006; 533-40
- Bruera, E. 2006: Errors in symptom intensity self-assessment by patients receiving outpatient palliative care,1059-1065.
- Chang VT, Hwang SS, Feuerman M. 2000: Validation of the Edmonton Symptom Assessment Scale, 2164-71.
- Chang VT, Hwang SS, Kasimis BS,1995: Symptom and quality of life survey of oncology patients at a VA medical center, 14-16.
- Cheryl Nekolaichuk, Sharon Watanabe & Crystal Beaumont & Asifa Mawani, 2008:The Edmonton symptom assessment system—what do patients think,91: 500-20).
- Chow E, Fung K, Panzarella T, Bezjak A, Danjoux C, Tannock I. A predictive model for survival in metastatic cancer patients attending an outpatient palliative radiotherapy clinic. *Int J Radiat Oncol Biol Phys* 2002;53:1291-302
- Crocker, L, Algina, J. and Jovanovich, 2006. Introduction to classical & modern test theory, 88-90
- Crystal Beaumont, Pautext, Sharon M. Watanabe and Cheryl L. Nekolaichuk 2004:The Edmonton Symptom Assessment System, a proposed tool for distress screening in cancer patients: development and refinement, 34-37.
- Davidson, Chris Pasero, Nancy Eksterowicz, Maggie Primeau, 2006: Assessing Pain in Kidney Patients with cancer, 55-57.
- Dellinger, A.(2005). Validity and the Review of Literature. *Research in the Schools*,12(2), 41-54.
- Dennis, Morey, MC., Snyder DC, Sloane R. Lippman, S.M., Klein, E.A., Goodman, 2009: supportive Care in Cancer. Volume 17, 97-102.
- Donna, L., Berry 2005: Patient-Centered Technologies: Enhancing Communication and Self-Care for Patients and Caregivers (Also, *Oncology nursing volume 21*. Palliative care and its proximity to end-of-life care issues frequently raise ethical issues for patients,63-68.
- Dudgeon, DJ., Harlos M, Clinch JJ, 2006: The Edmonton symptom Assessment Scale (ESAS) as an audit tool, 465-47.
- Ferrell, BR., Grant M, Ritchey KJ, Ropchan R, Rivera LM. 1993; The pain resource nurse training program: a unique approach to pain management. *J Pain Symptom Manage*, 549-556.

- Herr, K., Bjoro K, Decker S. 2006: Tools for assessment of pain in nonverbal older adults with dementia: a state-of-the-science review. *Journal of Pain & Symptom Management*,170-92.
- Higgins, Idson, C. L., Freitas, A. L., Spiegel, S. 2006: Handbook for Systematic,Reviews of Interventions: The Cochrane Library,49-51.
- Irmelin Bergh and Kearney M., Crystal Beaumont, 2011: Palliative medicine and how palliative cancer patients interpret and respond to the Edmonton Symptom Assessment System, 88-92.
- Jeff Myers, Sharon M. Watanabe, MD, Cheryl Nikolaichuk, PhD, Crystal Beaumont, BSc, Laureeen Johnson, RN., MD, and Florian Strasser, MD; A multicenter study comparing two numerical versions of the Edmonton Symptom Assessment System in Palliative care patients.
- Johnson, B., & Christensen, L. (2004). Educational research: Qualitative, Qualitative, and mixed approaches(2nd edition). Boston, MA: Pearson Education Inc.
- Judith, A., Paice and Betty Ferrell, 2011 : A Cancer Journal for Clinicians Volume 61, 157-182.
- Kimball, Ralph; Joe Caserta (2008). The Data Warehouse ETL Toolkit (2nd edition). New York: Wiley. ISBN 978-0-470-14977-5
- Kimberly, B., Chapman, Kim J. Burchiel. 2002: Nursing and Pain Surgical management of pain, 77-78
- Kimberly, B., Chapman, MS, RN Nursing and Pain 2009: Procedural Pain Management and Clinical Recommendations,21-25.
- Kirkova, J.,, Davis MP, Walsh D, et al. Cancer symptom assessment instruments: a systemic review. *J CLin Oncol* 2006;24:1459-1473
- Martin Moran. 2010: European Association for Palliative Care (EAPC) Lisbon, Portugal,18-21.
- McDowell, J., and Clark R. 2007, Pain and the administration of analgesia: what nurses say,175-188.
- Messick 1989: Educational Measurement, third edition. New York: American Council on Education,13-103.
- Moro,C., Brunelli C, Miccinesi G, 2006; Edmonton symptom assessment scale: Italian validation in two palliative care settings,30-37.
- Nikolaichuk, Eidg. Forschungsanstalt für Obst-, Wein- und, 2008: Development of a series of validation studies for the ESAS, 23-24.
- Pasero,C., & McCaffery, M,2002: When Patients Can't Report Pain. *American Journal of Nursing*,59-60. Also, Pasero 2000 Edition,22-23, also 59-60.
- Patton, MQ., 2002: Qualitative research & evaluation methods (3rd ed.),43
- Pautex, S., Berger A, Chatelain C, Herrmann F, Zulian GB: 2005: Symptom assessment in elderly cancer patients receiving palliative care,54-56.
- Periyakoil, VJ., Hallenback J, 2002: Identifying and managing preparatory grief and depression in end of life,2002,p.65:883-890. (Also, Volume 11, Number 3, 23-24).
- Phillip, J., Smith WB, Craft P, Lickiss N. 1998; Concurrent validity of the modified Edmonton Symptom Assessment System with the Rotterdam Symptom Checklist and the Brief Pain Inventory,539-41.

- Poulson and Wallace, 2004: a reviewer's critical account designed to convince an audience,25-30
- Puntillo, KA., Stannard D, Miaskowski C, Kehrle K, Gleeson S. 2002;Use of a pain assessment and intervention (P.A.I.N.) tool in critical care nursing practice: Nurses' evaluations. *Heart Lung*, 303-314.
- Rees, E., Hardy J, Ling J, Bradley K, A'Hern R. 1998; The use of the Edmonton Symptom Assessment Scale (ESAS) *Palliative Medicine* 75-82.
- Richardson, L.,A., Greta Cummings, Patricia D Biondo, David Campbell, Carla Stiles,2010: *Palliative Medicine*, 29-46.
- Shannon, K., Bucknall T. 2003: Pain assessment in critical care: what we have learnt from research. *Intensive and Critical Care Nursing*, 154-162.
- Slevin, ML., SE Nichols, SM Downer, P Wilson, TA Lister, S Arnott², J Maher³,RL Souhami⁴, JS Tobias⁵, AH Goldstone⁶ and M Cody, 2006: Emotional support for cancer patients, 1275-1277.
- Sinatra, S., Raymond 2009: Pain management & Palliative care,29-33. Stromgren AS, Goldschmidt D, Groenvold M, et al, 2002: Self-assessment in cancer patients referred to palliative care: a study of feasibility and symptom epidemiology,*94*:p.512-20
- Strongmen, Marianne Dees, Myrra Vernooij-Dassen, Wim Dekkers, Chris van Weel, 2002: Unbearable suffering of patients with cancer (*Psycho-Oncology*),339-352.
- Sun, V., Borneman T, Piper B, Koczywas M, Ferrell B. 2008: Barriers to pain assessment and management in cancer survivorship.*J Cancer Surviv*, 2: 65-71.
- Thomas, D., 2003: A general inductive approach for qualitative data analysis. Available at http://www.fmhs.auckland.ac.nz/soph/centres/hrmas/_docs/Inductive2003.pdf.
- Tranfield, Denyer and Smart,2003: A Methodology for Developing Evidence-Informed Management Knowledge by Means of Systematic Review,207-222.
- Van den Beuken, Everdingen MH., de Rijke JM, Kessels AG, Schouten HC, van Kleef M, Patijn J. 2007: Prevalence of pain in patients with cancer: a systematic review of the past 40 years,1437-1449.
- Villanueva MR, Smith TL, Erickson JS, Lee AC, Singer CM. 2003: Pain Assessment for the Demented Elderly (PADE): reliability and validity of a new measure. *Journal of the American Medical Directors Association* ,1-8.
- Warden, V., Hurley AC, Volicer L. 2003;Development and Psychometric Evaluation of the Pain Assessment in Advanced Dementia (PAINAD) Scale. *Journal of the American Medical Directors Association*,9-15.
- Watanabe S, McKinnon S, Macmillan K, Hanson J. 2006: Palliative care nurses' perception of the Edmonton 21-23.
- Woods, achon, ML., Kristjanson, L., & Higginson, 2000: Users' views on palliative care services: ethical implications. *Nursing in Ethics* 7,314-326
- Young, J., Kim, Sook Cho, Jae Ho Lee, Ji Hyun Kim, Eun Jung Lee, Jong Hyock Park, Jin Seok Lee, Yoon Kim, 2007 : *Physician journal of palliative medicine*,576-584.
- ÖZNUR USTA YEĞİLBALKAN¹, NİLAY ÖZKÜTÜK², AYFER KARADAKOVAN¹, TÜLAY TURGUT³, BURCU KAZGAN³,2008: Validity and Reliability of the Edmonton Symptom Assessment Scale in Turkish Cancer Patients,4-12.

Electronic sources:

A review of the reliability and validity of the Edmonton Symptom Assessment System:
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2644623/> (Downloaded on 22.06.2011)

Depression in Palliative Care <http://www.aahpm.org/pdf/depression.pdf>
 (downloaded 6.4.2011).

Guidelines for using the Edmonton Symptom Assessment System (ESAS)
http://www.empainline.org/linked_site_content/pdf/Edmonton%20FunctionI%20Assess%20System.pdf(downloaded on 5.7.2010).

NHS Centre for Reviews and Dissemination, 2001,
http://www.medepi.net/meta/guidelines/Overview_CRD_Guidelines.pdf(downloaded on 21.11.2011)

Purpose of the ESAS

<https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=13262> (downloaded on 6.7.2011).

Regional Palliative care program
[http://www.palliative.org/pc/rpcp/rpcpldx.html\(RPCP\)](http://www.palliative.org/pc/rpcp/rpcpldx.html(RPCP))(downloaded on 1.11.2011)

Research methodology

<http://uir.unisa.ac.za/bitstream/handle/10500/2231/04chapter3.pdf;jsessionid=447A69D531768873DF605C0F2DC78DE8?sequence=5>(downloaded on 6.7.2010).

World Health Organization. 'WHO Definition of Palliative Care', <http://www.who.int/cancer/palliative/definition/en/> (2010, accessed July 2010)

The ESAS Structure:

<https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=13846>(downloaded on 6.8.2010).

Validation of the Edmonton Symptom Assessment Scale.

<http://www.ncbi.nlm.nih.gov/pubmed/10813730>(downloaded on 1.11.2011)

WHO's definition of palliative care appropriate for children and their families; 1998a

<http://www.who.int/cancer/palliative/definition/en/>(downloaded on 21.11.2011)

Appendices

Appendix 1 Data Analysis articles

Author and the year of publication	Title	Setting and diagnosis	Method of data analysis	Study focus	Findings relevant to this study
Chang et al. 2000	Validation of the Edmonton Symptom Assessment Scale	Medical oncology outpatient clinic, inpatient unit; cancer	Quantitative analysis	To validate the ESAS in a different population of patients	ESAS can be used in both young and elderly cancer patients.
Stromgren et al. 2002	Self-assessment in cancer patients referred to palliative care: a study of feasibility and symptom epidemiology	PCU; cancer	Quantitative analysis	To evaluate the content validity of selected patient self-assessment questionnaires, including the ESAS, to determine Which symptoms or problems to Measure for the evaluation of palliative care programs.	Patient's view and that of the caregivers may vary on how they interpret the ESAS.
Pautex et al. 2003	The Edmonton Symptom Assessment System, a proposed tool for distress screening in cancer patients: development and refinement	Geriatric hospital; cancer	Quantitative analysis	To examine the concordance of symptom assessment among the multiple raters in French-speaking elderly patients with an advanced cancer benefiting from palliative care.	Interdisciplinary assessment is a valid surrogate to self-assessment by the patient so as to get clear results.
Nikolaichuk et al. 2008	Development of a series of validation studies for the ESAS	Division of palliative care medicine; department of oncology	Quantitative analysis	The Edmonton Symptom Assessment System: a 15-year retrospective review of validation studies (1991-2006)	The use of varying instrument formats and limited psychometric evidence support the need for further ESAS validation studies, including the involvement of patients.

ÖZNUR USTA et al. 2008	Validity and Reliability of the Edmonton Symptom Assessment Scale in Turkish Cancer Patients	Chemotherapy unit (cancer patients)	Quantitative analysis	Validity and Reliability of the Edmonton Symptom Assessment Scale in Turkish Cancer Patients	The ESAS is a valid tool for use with patients in the medical oncology group. The ESAS primarily evaluated physical wellness. This tool can be used in future studies for evaluation of symptoms.
Sharon Watanabe et al.2008	Edmonton symptom assessment system—what do patients think	Pain and Symptom Control Consultation Service(cancer patients)	Quantitative analysis	The Edmonton symptom assessment system—what do patients think?	Modification of the tool and administration process may be warranted, but further study in other populations is needed.
L.A. Richardson et al. 2009	Palliative Medicine	Emotional symptoms	Quantitative analysis	A review of the reliability and validity of the Edmonton Symptom Assessment System	ESAS is reliable, but it has restricted validity, and its use requires a sound clinical process to help interpret scores and to give them an appropriate level of attention.
Dr. Martin Moran et al.2010	ESAS and Elderly terminally ill Population	Glenrose rehabilitation hospital(Geriatric setting)	Quantitative analysis	Is the Edmonton Symptom Assessment Scale(ESAS) Valid for use in an elderly Population	Elderly cancer patients without cognitive failure and in stable general condition are consistent in their symptom assessment thus be a valid raters.

Irmelin Bergh et al. 2011	Palliative medicine and how palliative cancer patients interpret and respond to the Edmonton Symptom Assessment System	Palliative medicine unit(cancer patients)	Qualitative analysis	A qualitative study of how palliative cancer patients interpret and respond to the Edmonton Symptom Assessment System.	The use of varying instrument formats and limited psychometric evidence support the need for further ESAS validation studies, including the involvement of patients.

Appendix 2: Symptoms on the ESAS

Edmonton Symptom Assessment System (ESAS)

Please circle the number that best describes:

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
Not tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
Not nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
Not depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
Not anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Not drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of wellbeing
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
Other problem	0	1	2	3	4	5	6	7	8	9	10	

Patient's Name _____
 Date _____ Time _____

- Complete by (check one)
- Patient
 - Caregiver
 - Caregiver assisted

BODY DIAGRAM ON REVERSE SIDE

August, 2006

Used with permission from the Regional Palliative Care Program, Capital Health, Edmonton, Alberta, 2006

Appendix 3 The ESAS physical representation

Please mark on these pictures where it is you hurt.

