

# Decision Support Based Needs Assessment for Cancer Patients

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## Abstract

Regular assessment of wellness or quality of life for patients throughout a cancer journey is important so as to identify aspects of life that could lead to distress and impede recovery or acceptance. The emerging trends in assessment are to deploy validated, quality of life instruments on touchscreen computers in medical waiting rooms. However, these add to workload of health care professionals and can be impersonal for patients to use. In this article, an alternate approach is presented that involves a decision support system with natural dialogue that elicits the patient's specific context in a far finer grained manner than is possible with questionnaire based instruments. The system includes a model of heuristics that health care professionals in a locality use to make inferences regarding a patient's quality of life and avenues for referral.

*Keywords:* Needs assessment, Decision support, Supportive care, Cancer

## 1 Introduction

Numerous studies and reports have identified that many cancer patients have concerns with transport, finances, relationships, spirituality, pain, home, personal care and other facets of life over and above medical issues. Further, concerns impact on the morale of the patient and threaten to compromise positive attitudes to treatment or acceptance of the disease. (Gerber 2001)

Currently, the medical profession does not systematically include assessments of a patient's overall well-being and concerns into patient care. Specialist health care professionals serving cancer patients are typically faced with enormous time constraints.

Workflows and the realities of medical specialisations are designed to optimise human resources and often make it difficult for professionals to get to know patients sufficiently well to make an assessment of concerns outside the sphere of their medical speciality. The approach currently emerging in response to this problem involves the development of short questionnaire based instruments, rigorously validated and presented to patients while they wait for professionals or treatment. The first of these instruments to be used in Australia was developed by Foot (1995) and was to be used to specifically evaluate the needs of cancer patients. The Cancer Needs Questionnaire (CNQ) identified three levels of need (low, moderate, high) and two levels of no-need (no need, need satisfied). Since, then many other instruments, surveyed below, that have been validated to various degrees of rigor, have emerged.

The instruments are typically paper based and provided to patients to complete while waiting for a health care professional. However, processing the questionnaire data adds to the workload of health care professionals so has proven to be less than popular. The response to this has been to develop computer based versions with easy to use touch screens installed in waiting rooms for patients to use prior to a consultation.

The central claim of this paper is that the use of validated instruments and technological devices installed in waiting rooms, while possibly effective, does not put cancer patients at the centre of their treatment. Prompting patients who have a life threatening illness to indicate intimate personal details such as their level of distress, the quality of their sex life, or their reaction to being increasingly burdensome on their carer to a computer screen mounted on the wall of a waiting room does not obviously empower patients.

In this article, we advance an alternative approach where heuristics that health care professionals use to make a judgement of a patient's well being are modelled and embedded in a web based decision support system that patients can access from their homes, waiting rooms or mobile devices. The system incorporates question and answer sequences that are designed to be as natural and sensitive to a patient's specific context as possible.

The system is designed to be very readily extensible so health care professionals (or patients) who think of a need currently not catered for, can suggest questions that

patients might benefit from being asked, and have new questions-answer sequences entered. The approach can be conceived of as a Wikipedia style approach where the system evolves with user input and stands in contrast to the Britannica approach, more inflexible yet more rigorously validated.

A conventional decision support technology based on rule based representation is not sufficiently flexible for the extensibility required because any suggestion for a change in content would need to be executed by specialist knowledge engineers. Instead a relatively simple approach described below that permits the flexibility required, has been developed.

Currently, the system has been implemented and populated with rudimentary question-answer sequences. A system infers a snapshot of the state of wellness of a patient using basic criteria that can readily be extended. The system also infers recommendations for actions the patient or health care professional can take. The patient is expected to use the web based system on the internet in the comfort of their home and ultimately grant access rights to their health care professionals or take a print out of the system inference to their next visit. In this way, the report becomes a useful addition to the health care professional's tasks without adding to their workload and importantly, keeps the patient at the centre of their treatment.

This article reports on progress to date with this approach. The next phase of this project involves a trial to gauge the extent to which health care professionals and patients are likely to benefit from the systems inferences and contribute to its expansion. In the next section of this paper a review of the literature that identifies unmet needs as an issue and quality of life and other instruments that have been advanced in response to the need, is presented. Following that, the design of the system and pilot is described.

## **2 Wellness, needs and quality of life**

Gerber (2001) identified that cancer hospital inpatients had diverse needs which are best understood in order to promote an improvement in the quality of care. Wen and Gustafson (2004) also emphasise the importance of an assessment of patient needs, satisfaction and quality of life. They reviewed the assessment instruments of needs experienced by cancer patients and their families and conclude that a careful assessment of patients' needs is central to the whole process of providing care.

According to Siegal (1994), cancer patients can encounter financial problems as income often diminishes while medical expenses increase. Further, (Houts et al 1984) discovered that as a patient's functional capacity diminishes, out-of-pocket expenses rise due to an increase in needs for necessities such as transportation, child care, home care services, extra or specific foods, clothing, and lost income and wages. Berkman (1993) also found that out-of-pocket expenses coupled with gaps in medical insurance coverage cause long-term financial difficulty and jeopardize patients' ability to obtain or keep health insurance coverage leading to spiralling problems. Mor et al (1987) found that 41 percent of households studied reported a 50% increase in expenses and 16 percent of

households studied were unable to meet their monthly bills.

Bryan et al (1991) reported that cancer patients face a variety of problems related to transportation including availability of, and access to public transport, difficulties associated with driving or having others drive and travel. For patients in regional areas, travel can require accommodation, which involves logistic challenges. Among elderly cancer patients, Goodwin et al (2003) found that those with reduced access to transportation were four times less likely to receive radiation therapy following surgical treatment.

Financial and transport concerns are tangible and relatively easily recognised by patients themselves. Other issues may not be so readily apparent but no less concerning. Surbone and Baider (2010) discuss the spiritual dimension involving cancer patients. Rainbird et al (2005) identified seven categories of needs for the cancer patient: Medical communication and information, Psychological/emotional, Daily living, Financial, Dealing with symptoms, Spiritual and Social.

A number of instruments have been developed in recent years to assess the diversity of needs. Foot et al. (1995) developed the first Australian Survey to evaluate the needs of the cancer patients known as the Cancer Needs Questionnaire (CNQ). Another commonly used questionnaire is the Supportive Care Needs Survey advanced by Bonevski (2000). This survey includes issues related to sexuality. The questionnaire developed by Osse (2005) is tailored for palliative care: the Problems and Needs in Palliative Care questionnaire (PNPC).

The Cancer Rehabilitation Evaluation System (CARES) advanced by Schag (1990) measures need items from six domains, first on a five-point scale to indicate whether the need applies and then whether additional help is required. Tamburini et al (2000) developed a Needs Evaluation Questionnaire (NEQ) to evaluate the informative, psychological, social and practical needs of hospitalised cancer patients that would help the medical staff as well as the cancer patients. The NEQ is a standardized questionnaire, consisting of 23 items that has been empirically validated. It assesses the following needs: information concerning diagnosis or prognosis, information concerning treatment, communication, home assistance, financial and other support.

The most pressing observation to make from the plethora of instruments that have been developed is that they vary based on the needs covered, the intended end user and the patient context. This strongly suggests that a single instrument is unlikely to be well suited to every context involving the practice of health care with cancer patients. For instance, health care professionals in remote areas, may require that transport segment of instruments be more sophisticated than in city areas. In localities characterised with patients from high populations of minority groups and practitioners from majority cultures, psycho-social assessments focused on cultural issues may be pertinent in a way that they are not in homogeneous localities.

The development of a validated instrument for each locality is impractical and too rigid in that preferences of

health care professionals and patients in a community change over time. An alternative to developing a validated instrument customised for each locality, or a universal one specific to no single locality, is to develop a decision support system designed to evolve locally to suit the characteristics of each community over time. This does not mean that empirical validation of the decision support system is not important but only that validation studies need to be postponed until the decision support system's knowledge base has been populated to a point where there is widespread albeit informal agreement that the system attempts to tap into the needs that health care professionals and patients in a locality consider important. In the next section, the system developed for this purpose is described. The system currently has been seeded with initial question and answer sequences and some referral heuristics. The next phase of the study will involve refinement of the prototype in a test locality prior to wider deployment.

### 3 NADSS Needs Assessment Decision Support System

The needs assessment approach adopted in this study involves the development of a decision support system by capturing the heuristics health care professionals deploy when engaging with patients to make an assessment. Ultimately, health care professionals engage patients in a dialogue and apply heuristics that have evolved with experience to determine appropriate questions to ask given a patient's previous answers and finally, advance an assessment regarding the patient's needs.

Koers et al (1989) had found that the sequence of questions an expert asks is more important than the logical structure of knowledge in a domain for the user acceptability of a system. User acceptance is important for any software system but is particularly critical in the field of needs assessment for cancer patients because patients will be expected to take themselves through a consultation, perhaps many times, during their cancer journey. However, acceptance is made difficult because patients may tire easily; they may have heightened sensitivity to quality of life prompts and may have limited computer experience or skills.

Kawamoto et al (2005) identify critical success factors in the successful deployment of clinical decision support systems that include: useability, integration into clinician's existing workflow, provision of a recommendation, integration with other systems and provision of results to patients and clinicians. The current approach is designed to accommodate each of these factors with the exception of the integration with other systems. The transfer of data between health care professionals systems and the needs system, and vice-versa requires that flexibility in databases that most hospital systems currently do not have. In the future, a ubiquitous electronic health record will facilitate this integration.

The current approach involved capturing the question and answer sequences that health care professionals were likely to use in discursive engages with patients leading to heuristic assessments of their needs. Three of the investigators who collectively had many years experience in modelling heuristics and caring for patients derived

question and answer sequences that seemed plausible. The first question prompts the patient to select a need category labelled 'Talking Points' as illustrated in Figure 1. Categories defined to date were: Financial, Physical, Home/Family, Spiritual, Transport and Social.

The first prompt in the Physical category is:  
*What would you like to talk about?*

- Lets talk about pain
- Lets talk about personal care



Figure 1 Talking point menu

If Lets talk about pain is selected the following prompt appears:

*Are you in pain right now?*

- I would be if I wasn't managing it
- I am in some pain right now
- No, not really

If I would be if I wasn't managing it was selected then the following prompt is presented:

*Which of these applies to you more?*

- Its increasingly difficult to manage the pain
- Its currently under control
- Its currently under control but I'm concerned about coping in the future

The consultation continues until an end point is reached where the patient is returned to the *Talking points* menu where another category or a system exit can be selected. On exit, the system performs a needs assessment and generates a report as illustrated in Figure 2.

The question and answer sequence is conceptually equivalent to a decision tree where nodes represent questions and arcs emanating from each node represent alternate answers. This is conceptually equivalent to sets of IF-THEN rules however, the decision support system advanced here varies the traditional approach. Instead of encoding a final assessment in the leaf or conclusion nodes of the tree, the approach advanced here sets variables associated with each arc to values specified by the health care professional and knowledge engineer. These variables represent something about the state of the

patient. For instance, a variable *Anxiety*, initially set to 0, is incremented by 1 when the user responds that he or she would be pain if they were not managing it. The heuristic used here involves the notion that a small level of anxiety is associated with the management of pain.

On conclusion of the consultation, the system compares the variable's values to threshold values linked to suggested actions. For example, a total *Anxiety* score between 3 and 6 triggers the suggestion that the patient should be referred to a social worker. A total anxiety score greater than 6 triggers the suggestion that the patient should be referred to a consultant. The **Snapshot** section of the report produced depicted in Figure 2 derives directly from the variable scores and the **Suggestion** section derives from comparing the scores to thresholds associated with suggested actions.

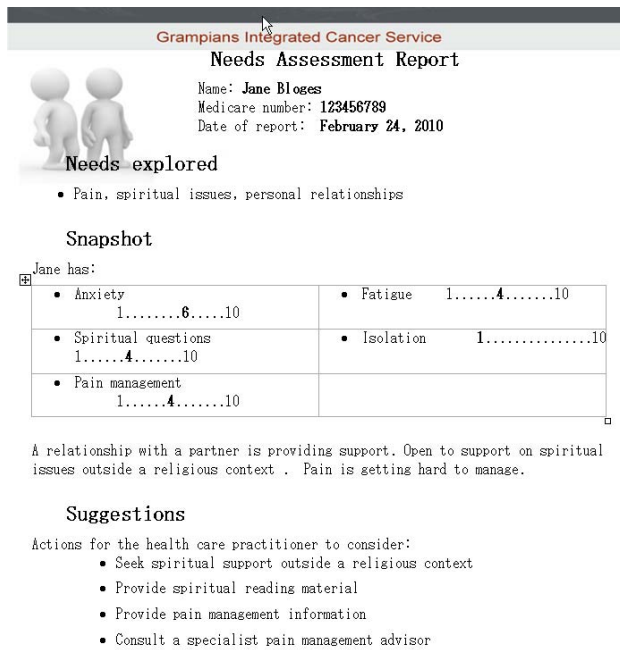


Figure 2 Needs assessment report

This Snapshot and Suggested action mechanism was designed for the following reasons:

- Variables that represent a snapshot of the patient's state were considered useful for health care professionals to quickly gain an overview of a patient's state;
- The suggested actions encode heuristics that experienced professionals use to trigger possible remedial actions. This inference provides health care professionals that enhances and facilitates their role. This is in contrast to questionnaires that identify a need but assume the professional will draw the appropriate inference in inferring a remedial action. This adds cognitive and time load on the professional;
- Encoding heuristics as Snapshot variables and Suggested action heuristics permits the question and answer sequences to be designed to be as natural as possible;

- The approach is readily extensible. Knowledge engineers can associate any number of variables to each answer and assign a numerical value to any variable to represent the extent to which that state is enhanced by the selected answer.

Four modules were deployed within the Patient Needs Assessment System. These were:

- the Expert Knowledge base,
- the Inferencing or Decision Support system,
- the User Interface and;
- the Content Management System.

Expert knowledge guided the content and direction of the questions that patients consider.

The Inferencing System uses two matrices of variables for each category domain. In the first, a score is associated with a variable for each user selected response to a question as presented in Table 1 .

It is increasingly difficult to manage the pain	
Variable	Score
Pain	5
Anxiety	2
Fatigue	1
Close others	1

Table 1: Variables and scores on a pain response

The heuristics captured by the investigators as knowledge engineers illustrated in Table 1 involve the belief that a patient finding it increasingly difficult to manage pain will have a little anxiety, a little fatigue and will place an addition strain on others close to them.

Heuristics regarding which professional, if any, the patient should be referred to, is captured as a score on each variable as illustrated in Table 2. The actions in the table depend heavily on the local context. In a region without pain specialists, health care professionals may refer patients to local psychologists so they would simply change the entry in the table.

The User Interface deploys the Bellaswan Content Management System ([www.bellaswan.com.au](http://www.bellaswan.com.au)). Some handcrafting was necessary at the higher application interface level to ensure the categories and conversation topics are each presented in a way that fosters trust from both patient and professional. A template thereafter uses a call-back method that populates the lower-level decision tree conversation points. The consistency of content placement is important. If system-generated content is misplaced, inconsistent or overlaps other content, the perception of quality is compromised. Reassurance of

how data that is collected from users must also be clear to patients and professionals from the outset.

Referral inference for the Pain variable	
Score	Health Care Professional
7 or more	Recommend a pain specialist
Between 3 and 7	Recommend a GP
Between 1 and 3	Provide pain management information
Less than 1	No action required

Table 2: Referral scores for the variable Pain

The Content Management System (CMS) retrieves, stores, processes and returns data to the interface. As the patient explores the conversation topics and makes selections, a snapshot of their own “Story so far” is displayed on-screen and can be printed or emailed at any time. This acts as a narrative summary of the current consultation.

#### 4 Conclusion

Many instruments have been developed and validated to elicit the physical, financial, transport, psychological, social, sexual, spiritual, pain management and informational needs of cancer patients. To reduce the workload on health care professionals many instruments are being converted to touchscreen, computer implementations installed in waiting rooms. However, these can be uncomfortable for patients to access and do not cater for preferences that professionals or patients have in local communities. An alternative approach is presented that involves the development of a decision support system that presents the patient with a question and answer dialogue that is more natural and can be tailored to suit the context of the community and patient. The decision support system is designed to be very easily extended so that, over time, it evolves to suit local preferences. A system has been designed and populated with an initial knowledge base. Further research will explore the extent to which patients and health care professionals can enhance the knowledge base and derive benefits without adding to the workload of current staff.

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