How To:

Implement Automated Screening for Problem-Related Distress in Cancer Settings

Authors:

Karen Clark, MS

Matthew Loscalzo, MSW

Sheri & Les Biller Patient and Family Resource Center

1500 East Duarte Road,

Duarte, CA. 91010-3000

Contents:

- 1. Overview of automated data collection methods
- 2. Developmental Phase

Patient-Friendly Program Content

Program Design

SupportScreen

Triage

Hardware

Touch Screen Process

3. Implementation phase

Barriers and Solutions

- 4. Benefits
- 5. Conclusions
- 6. References

1. Overview of Automated Data Collection Methods

Automated methods for gathering patient self-report data are key to ensuring overall efficiency and cost-effectiveness for psychosocial screening programs. In this report, we present how to implement automated screening for identifying and triaging problem-related distress in cancer settings.

Several studies suggest that electronic methods of data collection is easy, quick, reliable, and acceptable to patients, all of which are important components for integration into routine oncology practice. ^{1 2 3 4 5} Innovative computer touch screen technology is one of the more popular electronic methods, and its application to patient care is gaining attention within the health care community.^{6 7} Touch screen technology is a keyboard-free interface where users can input data onto the computer screen using a pen or their fingers. Velikova *et al.* ² reported that the touch screen is well-accepted and provides good quality data while minimizing missing responses and the need to decipher ambiguous data. In a recent study of 450 cancer patients, Allenby *et al.* ⁶ found that although half the patients report having no prior computer experience, 99% of them find the touch screen easy to use.

A major advantage of touch screen technology, also reported in the literature, is that the results are readily available to generate reports for immediate use by the medical staff. ^{2 8 9} The implication is that patients can receive immediate tailored assistance while saving staff time. A recent report by Taenzer *et al.*³ on the use of an electronic quality of life (QOL) survey finds that electronic data collection is a simple, time-efficient and well-accepted method of improving patient-provider communication in a busy outpatient clinic. More specifically, this study reports that the computerized survey increased detection of QOL problems during clinic appointment times and indicates a trend towards a larger number of problems charted and addressed.

The early identification of patient problems is essential to relieve distress, prevent crises and minimize system disruption. Supported by the literature ¹⁰ ¹¹ ¹² ¹³ the National Comprehensive Cancer Network (NCCN) recommends distress screening for all cancer patients to address problems before a crisis develops and necessitates intervention. Taking the lead from advances in pain management integration into standard medical care, Bultz et al. 14 15 have advocated that distress be designated the Sixth Vital Sign. Recognition of the importance of distress as part of the overall health of an individual is a significant advance in cancer care. Based on 10 years of experience in cancer problem-related distress screening, ¹⁶ we developed a biopsychosocial screening instrument titled "How Can We Help You and Your Family?" 17 18 As the title demonstrates, this is a patientcentered process in which, by design, the direct benefits to the patient and family are immediately self-evident. Initially, a paper version of the questionnaire was used to help clinicians gain a better understanding of the type of biopsychosocial problems experienced by patients. Some of the major limitations of the paper version were that it was time-consuming for staff to enter, verify and interpret. In addition, the information was not consistently delivered to health care team professionals in real-time for discussion during consultation. The purpose of this report is to describe the implementation of the touch screen technology as an effective psychosocial screening tool with immediate clinical utility.

2. Developmental Phase

The first step to introducing an automated screening program is to create a multi-disciplinary team. This pulls on the expertise of the team members and engages them in the process. Generally the consistent of but not limited to: psychiatrists, psychologists, social workers, nurses, oncologists, researchers and information technology specialists. The team determines program content, triage criteria and hardware all tailored to the individual setting. This collaboration is essential from day one to promote program investment and a sense of commitment to the overall vision.

Patient-Friendly Program Content

From the very first page of the touch screen the message to patients should convey that the automated screening instrument will be of immediate value to them and not merely another hospital requirement without obvious benefits. One example of this is to open the touch screen with a letter from the patient's physician welcoming them to partner with the health care team and to frame the screening process. This welcome letter should communicate to the patient how the screening process will enable them to be part of the health care team and how this information will be helpful in planning their care and to get to know the patient as a whole person. It is also recommended that this letter include a picture of the physician and/or the health care team. This letter should also let the patient know that the information will be shared with the team and can also be used to guide the patient in how to complete the touch screen.

Although there are a number of validated psychosocial screening instruments, they are primarily used in research settings and are not particularly patient-friendly. This has been demonstrated by the lack of systematic psychosocial screening in clinical settings. However, one example of a patient-friendly biopsychosocial screening instrument is the *You, Your Family and City of Hope are a Team*. This problem-related distress screening instrument is based on earlier versions of the *How Can We Help You and Your Family*? (both paper-based ¹⁸ and electronic¹⁹) of approximately 10,000 screened cancer patients, with a full range of diagnoses and demographics. *You, Your Family and City of Hope are a Team* is available in both English and Spanish. The 53-question screening instrument, using simple language, addresses physical, practical, social, psychological and spiritual problems (See Figure 2). Patients are asked to rate each of the 53 problems, How much of a problem is this for you? (on five-point scale from Not a Problem to Very Severe Problem). In addition, patients are asked if they are requesting to Talk with a Member of the Team and/or have us Provide Written Information or Nothing Needed at this Time.

The You, Your Family and City of Hope are a Team also contains domains that are not included in other validated screening instruments (rehabilitation, swelling, nutrition, etc). Therefore, there are no validated biopsychosocial screening instruments that can be used to accomplish the same clinical goals (problem identification and triage) as the You, Your Family and City of Hope are a Team.

Program Design

The touch screen program was built using Active Server Pages (ASP) with VBscript and JavaScript. In order to minimize missing data, a feature was built into the system such that the patient could

only proceed to the next screen once every question had been answered. Additional response options were also added ("prefer not to answer" and "do not know") so that patients did not feel forced to provide an answer for each and every question. Underrepresented populations were taken into account in the development of this program. For example, larger font was used for the elderly population, visual and audio cues were used to signal page changes and, as mentioned above, a Spanish version was also developed. Two questions were presented per page and patients entered their responses by either touching the screen or using a stylus to select the corresponding buttons on the screen. The most recent version of this touch screen program is called *SupportScreen*. *SupportScreen* was specifically designed to be a stand alone software program that easily interfaces with the most commonly used patient information systems.

SupportScreen

SupportScreen is an automated touch screen system that identifies and triages patient biopsychosocial problems in real-time. SupportScreen facilitates patient, physician and multi-specialist communication. SupportScreen also provides customized reports for research and clinical purposes. SupportScreen refers to the entire process-from initiation of patient responses to the generation of referrals and provision of resource and educational information.

Triage

After the content is selected, the next step is to determine the triage criteria for each of the biopsychosocial problems. At this point in the development process it is essential to meet with all the health care team members to determine the triage criteria. *SupportScreen* is a highly adaptable system used to meet the needs of patients. Triage criteria should be set based on the specific needs of patients, current resources available and staffing levels. In *SupportScreen* each item can precoded and electronically transmitted to a specific professional or resource in real-time. In addition, a copy of the notification is sent to the patient's physician, nurse and social worker to ensure effective communication. However, *SupportScreen* is designed to be highly flexible and where and to whom it directs the electronic triage information. The NCCN distress management guidelines ¹⁰ can be a helpful source of information in the development of triage and intervention.

In our experience, patients' responses triggered referrals in approximately 77% of the population. Each problem was linked to the appropriate health care team member for triage. For example, if a patient reported a pain distress level ≥ 4 , this information was immediately sent to the nurse, doctor and social worker. The items *pain* and *thoughts of ending my own life* were flagged and considered "hot buttons" which required immediate attention from a health care team member. Problems related to physical symptoms such as nausea and vomiting or recent weight loss were referred to a physician and/or nurse. Problems related to emotional, social and practical concerns such as *feeling down or depressed* or *feeling hopeless* were triaged to a social worker for an assessment and potential referral to psychology or psychiatry. Each health care team member was copied on all emails regarding the patient; this helped to ensure timely communication and clear delineation of responsibility for follow-up promoting continuity of care. However, *SupportScreen* easily changes

thresholds, criteria driven referrals, educational materials and data tracked through an easy to use web-based administrative screen. The administrative screen can be easily managed by someone with a moderate level of computer skills.

Hardware

SupportScreen is a highly flexible web-based interface that is designed to function efficiently on a wide variety of technology media (laptops, desktops, tablets, etc). Therefore, SupportScreen does not commit to anyone single hardware. Our team is constantly testing new hardware to see what is the most patient-friendly and cost efficient. We do not have any relationship with a hardware vendor. This enables our team to always be looking for better products to maximize SupportScreen. At City of Hope, the outpatient clinics have wireless Internet access, which made laptops a feasible option for the touch screen program. Kiosks were not used due to lack of space and privacy concerns. However, SupportScreen can be run from any computer with an internet connection, not only on a wireless system.

The touch screen process

In our experience, biopsychosocial screening needs to be made a part of the institution's standard of clinical care and not an "add on".

Figure 1 displays the *SupportScreen* clinic process. Each patient checks in for their appointment with the front desk staff. Front desk teams are given laminated copies of a script to post on their computers and to read to the patient. The script says, *We have a short questionnaire that we would like you to complete. By completing this form you will tell us how we can best work together with you as an effective team.* The front desk staff then identifies the patient by their medical record number or their name and birth date in *SupportScreen*. The patient is given a laptop with brief instructions and directed to find a comfortable place to sit and complete the screening instrument. The front desk staff is available to assist, although this is seldom necessary. *SupportScreen* takes approximately 12-15 minutes to complete.

As previously mentioned, each problem is linked to the appropriate health care team members. Thus, once criteria are met, an immediate Summary Report is generated listing all problems triggering referrals or requests to talk with the team. In the e-mail and printout, patient responses are categorized by the health care team member responsible for action. For example, the physician receives an e-mail in real-time listing all of the problem-related distress areas that required intervention, as well as a copy of the problem-related distress areas that requires assistance from other health care team members. A printout is also generated at the front desk and placed on the patient's chart to initiate communication between the health care team and the patient during their visit. Simultaneously, the raw data is sent to an Excel spreadsheet. These data are downloaded as needed for research, dissemination and program development.

Figure 1.

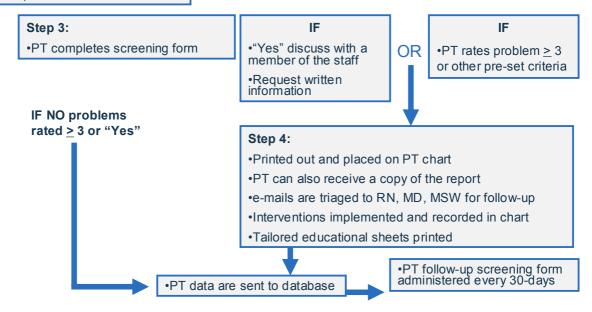
Step 1:

- •Patient (PT) checks in
- •Medical record number links to screening form

Step 2:

•Scripted instructions to complete screening form (select English or Spanish)

SupportScreen Process in the Clinic



3. Implementation Phase

To ensure that the implementation of the touch screen process goes as smoothly as possible, pilot testing is recommended. We suggest to start screening with a couple of physicians that are strong supporters of biopsychosocial screening. It is important to start slow, thus any problems that come up are made on a smaller scale and can be addressed immediately.

Although there was minimal initial resistance to the screening process by the physicians and nurses, our experiences clearly demonstrate that buy-in from the front desk staff handing out and retrieving the instrument was critical and that they needed to be actively engaged.

Table 1 lists the *barriers and solutions* of implementing the touch screen. Prior to implementation, marketing of the touch screen to the health care team should be conducted through e-mails, presentations at relevant meetings and by word-of-mouth. We also recommend several training sessions with the front desk staff to help increase motivation. Formal breakfast and lunch-time training sessions should include: a description of the project and background, a touch screen demonstration, role playing, scripts and training manuals. Follow-up meetings with the health care team should also be conducted to address any questions and concerns about the touch screen process. Throughout the implementation phase it is essential to continually reinforce the importance of the touch screen process for maximizing cancer patient care, as well as for discovery of new knowledge and the development of tailored programs.

Table 1: Barriers and Solutions in Implementing Automated Screening

Barriers	Solutions		
Lack of institutional support	Active engagement and integration of multi-disciplinary team to create and implement screening institution-wide		
Health care professionals fears/concerns about implementing biopsychosocial screening	Active engagement and integration of interdisciplinary team in all aspects of program development and evaluation		
• Time	Demonstration of brevity of instrument and simplicity of use		
Workload	Front load with extra staff during pilot phases while adjusting to extant clinic process		
Disruption of clinic flow	 No additional administrative staff required as is built into existing clinic encounters (instructions are scripted and manualized) 		
Resources (space, money and staffing)	Personal experience of benefits in tailored history-taking of the key areas identified in real-time		
Lack of comfort with emotional concerns	Automated triage to multi-specialists and resources in real-time		
	Automated and tailored written materials provided to patients in real-time		
Sense of control over clinical practice	Upfront costs are recuperated over time due to resource efficiencies		
Fear of change	Train colleagues in appropriate responses to emotional concerns		
• Feat of Change	Be immediately available to manage psychosocial problems in the clinical encounter		
	Summary Report of biopsychosocial concerns provided in real-time		
	Physician has ability to monitor and direct electronic triage and referrals in real- time		
	Demonstrate personal benefits to physicians, nurses and other professionals through daily experience with screening program		
	Start small, go slow, correcting as the program expands		
Lack of IT Department Support			
Fear of the unknown-something new	Part of a team much larger than IT		
Lack of time and resources	Institution sees you in a new way not just technical		
Endless competing projects	Active leader in every aspect of the program- development, presentation, publications royalties		
Protective impulses for what we have created "in-house"	Leading the development of new knowledge-Research		
Compatibility concerns	Hire additional staff		
Fear of data corruption	Hire different kinds of staff		
HIPPA as an excuse to do nothing now	Get to be creative		
HIPPA as an excuse to do nothing new Do not value the humanistic aspects of illness experience	Get to see your work from the beginning to the end user patients families,		
Change	community		
Turf	See the good you have created and how it helps		
Ego-competitiveness	Teach others the languages of IT and learn their language		
Ego competitiveness	Learn the more clinical aspects of health care leading to a more interesting profession		
	Be full partners in creating innovative programs and not just a technical "piece-meal service"		

Benefits

Quality of care, patient safety related to medical errors and resource deployment are all key areas of health care that can benefit from the potential innovations of a prospective, systematic, integrated system of electronic clinical data transfer, documentation and communication.

Several studies demonstrate the offsetting advantages of addressing psychosocial issues, despite the effort and cost of establishing an automated screening/triage system. These include cost benefits to hospitals providing psychosocial care, ²⁰ as well the potential for distress screening to predict and intervene in, patient treatment non-compliance, appointment-breaking ²¹ and clinical trial discontinuation. ²²

Physician time is increasingly consumed with administrative demands, such as authorization and utilization review, resulting in a decrease in the amount of time spent with patients. *SupportScreen* has the potential to optimize the patient's time spent with the physician through enhanced identification of key areas for discussion. Patients experience their clinical encounters as stressful and highly emotionally charged. Within this context, patient-physician communication is primarily focused on disease-directed information at the expense of critical biopsychosocial domains. *SupportScreen* teaches patients about common problems related to cancer and alerts physicians to the specific problems manifested by the patient during the clinical encounter. It can provide a common language, a normalization of problems and a decrease in concerns about stigma. For the health care team (physicians, nurses, support staff) the information is neatly organized, documented electronically and provides cues for referrals to other services, all in real-time.

Patients' families and caregivers, physicians, nurses and other health care professionals will also directly benefit from *SupportScreen*. See Table 2 for a detailed list of the benefits of *SupportScreen* for Patients and families, physicians and staff and the institution. Although *SupportScreen* presently focuses on cancer patients, the implications for other chronic illnesses are evident. Anyone confronted with the vicissitudes of chronic serious illness must first learn to effectively communicate with their health care team in order to adapt to their new reality, make difficult decisions, identify barriers to care and actively participate in rehabilitation and palliation. *SupportScreen* can become the foundation for an evolving partnership through systematic electronic communication between seriously ill patients, their health care team and the multi-specialists involved in their care.

Regardless of race, ethnicity or socioeconomic status, medical illness places stress on an individual's ability to function normally and alters the family/support dynamic. The biopsychosocial problems on *SupportScreen* can be readily modified to address pertinent issues related to a particular demographic or disease population. The creation of a system that can screen, identify problems, communicate, refer, and intervene has universal application. *SupportScreen* has national and international implications for the enhancement of clinical encounters in real-time by creating a model for other institutions.

Table 2: Benefits of Using Automated Screening

For Patients and Families

- User-friendly system to identify problems related to care
- Gives patients a voice and common language to partner with their health care providers
- Encourages open and honest communication with health care team
- Teaches patients about common problems other patients have encountered
- De-stigmatizes requests for help
- Raises expectations of psychosocial services being addressed
- Implements timely referrals to resources and supportive services
- Identifies personal needs related to medical care
- Promotes prioritization of immediate needs
- Provides tailored educational materials printed out in real-time
- Tailors support services to personal situation
- Creates a sense of order and control
- Improves continuity of care

For Physicians and Staff

- · Quickly and efficiently screens all patients as standard of clinical care
- Presents an organized list of problems
- Links ICD-9 codes to support medical charting and billing
- Takes less time to identify patient problems
- Identifies patients who are at high risk for disruption of clinic and lack of compliance
- Streamlines triage and referral to appropriate resources
- Protects time to focus more on their area of expertise
- Reduces data entry and illuminates verification burden
- Creates data bases for grants, publications and programs
- Easily exported to most commonly used software applications
- More efficient data interpretation

For the Institution

- · Raises the standard of clinical care
- Screens every new patient
- Increases patient satisfaction
- Identifies and triages patients in real-time
- Increases safety
- Minimizes disruption of processes and system
- Enhances staff efficiency
- Links ICD-9 codes to increases revenue
- Reduces administrative costs
- Fundraising opportunities
- Competitiveness in the market place
- Model for other institutions

4. Conclusions

SupportScreen can be applied to other types of research or programs and can be easily adapted to other health care settings, such as small community based clinical practices.

Future directions of *SupportScreen* are to integrate *SupportScreen* with the Electronic Medical Record System (EMR) at City of Hope. Integrating psychosocial data into the EMR in real-time will allow the health care team to communicate their assessments and treatment plans, identify referrals made and accepted, document the specific problems and concerns of patients and more easily perform automated quality assurance processes. An automated continuous-improvement feedback system feature will also be designed into *SupportScreen* and will be available at the push of a button for all users (patients, physicians, nurses and other health care professionals) at every communication transmission. This feedback button will be available in the Summary Report sent via e-mail to the health care team and in also the EMR system. In addition, electronic audit functions will be built into *SupportScreen* to evaluation the effectiveness of *SupportScreen* use in a clinical setting.

In addition, institutional metrics will be evaluated for cost savings to the hospital as a result of implementing the *SupportScreen* as a standard of clinical care. Future research needs to include outcome data to support the potential benefits of using touch screen technology.

Additional future applications and research plans of touch screen technology include testing the psychometric properties of the touch screen, as well as developing population-specific screening (e.g. pediatrics, geriatrics, survivorship) and implementing repeated screenings every 30 days or when starting a new treatment.

Furthermore, new ways to bring people closer together utilizing the most recent technological advances (i.e., cell phones and handhelds) will continue to be implemented and studied. Moving from automated screening to computerized full assessments of both patients and caregivers is the next logical step of this program and is currently in process at City of Hope. Future use of technology will help to bridge the gap between detection of problem-related distress and referrals for assessment or treatment; creating proactive approaches to whole-person centered care.

To find out more information about *SupportScreen* please e-mail: Karen Clark (kclark@coh.org) or Matthew Loscalzo (mloscalzo@coh.org).

Figure 2

Race- African American		Your Annual Household Income Level-	Language Prefer to Speak- English □			
Asian/Pacific Islander 🗌		<\$40,000.00 □	Armenian □			
Caucasian 🗆		\$40,000.00-\$100,000.00 \Bar	Chinese-Cantonese □			
Hispanic 🗆		>\$100,000.00	Chinese-Mandarin □			
Multi-racial			Farsi □			
Native American/Native A	Alaskan 🗆		Korean			
Unknown □		Your Highest Level of	Russian			
Other 🗆		Education-	American Sign Language □			
		Less than High School □	Spanish 🗆			
		Some High School □	Tagalog 🗆			
Present Relationship-		Completed High School □	Thai 🗓			
Divorced		Some College	Vietnamese □			
Married □		Completed College □	Other			
Living with Partner □		Beyond College □				
Single □		, v				
Separated □		Please take a few moments to:				
Widowed □	1. Rate each and every problem by circling a number 1 through 5.					

- 1. Rate each and every problem by circling a number 1 through 5.
- 2. Then, please circle for each and every problem what you need from the health care team.

Problems	Please rat	te each problen	1	Please tell us how we can best help you?
Transportation	1 2 Not a Mild Mo	3 4 oderate Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Finances	1 2 Not a Mild Mo	3 4 oderate Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Needing help coordinating my medical care	1 2 Not a Mild Mo	3 4 oderate Severe	5 Very Severe	Nothing needed at this time Talk with a member of the team
Sleeping	1 2 Not a Mild Mo	3 4 oderate Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Talking with the doctor	1 2 Not a Mild Mo	3 4 oderate Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Understanding my treatment options	1 2 Not a Mild Mo	3 4 oderate Severe	5 Very Severe	Nothing needed at this time Talk with a member of the team
Talking with health care team	1 2 Not a Mild Mo	3 4 oderate Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Talking with family, children and friends	1 2 Not a Mild Mo	3 4 oderate Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Managing my emotions	1 2	3 4 oderate Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Solving problems due to my illness	1 2 Not a Mild Mo	3 4 Severe	5 Very Severe	Nothing needed at this time Talk with a member of the team

Problems	Please	rate eacl	h proble	em	Please tell us how we can best help you?
Feeling irritable or angry	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Managing work, school or home life	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Talk with a member of the team
Becoming too ill to communicate my choices about medical care	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Worry about the future	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Questions and fear about end of life	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Finding community resources near where I live	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Getting medicines	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Talk with a member of the team
Spiritual or religious concerns	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Fear of medical procedures (needles, enclosed places, surgery)	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Ability to have children	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Controlling my urine or stool	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Talk with a member of the team
Physical appearance	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Feeling anxious or fearful	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Swelling	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Losing control of things that matter to me	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Feeling down or depressed	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Walking, climbing, stairs	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Talk with a member of the team

Problems	Please rate each problem			em	Please tell us how we can best help you?
Thinking clearly	1 2 Not a Mild	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Talk with a member of the team
Pain	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Side-effects of treatments	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Being unable to take care of myself	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Substance use-you or in your environment (drugs, alcohol, nicotine, prescription meds, other)	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Joint limitations (including jaw)	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Talk with a member of the team
Fatigue (feeling tired)	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Bowel movement/constipation	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Sexual function	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Thoughts of ending my own life	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Talk with a member of the team
How my family will cope	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Eating, chewing, or swallowing difficulties over the past week or two	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Talk with a member of the team
Feeling isolated, alone or abandoned	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Provide written information Talk with a member of the team
Recent weight change	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Talk with a member of the team
Nausea and vomiting	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Talk with a member of the team
Feeling hopeless	1 2 Not a Mild problem	3 Moderate	4 Severe	5 Very Severe	Nothing needed at this time Talk with a member of the team

Problems	Please rate each problem	Please tell us how we can best help you?
Needing practical help at home	1 2 3 4 5 Not a Mild Moderate Severe Very problem Severe	Nothing needed at this time Provide written information Talk with a member of the team
Health insurance	1 2 3 4 5 Not a Mild Moderate Severe Very problem	Nothing needed at this time Provide written information Talk with a member of the team
My ability to cope	1 2 3 4 5 Not a Mild Moderate Severe Very problem Severe	Nothing needed at this time Provide written information Talk with a member of the team
Speech	1 2 3 4 5 Not a Mild Moderate Severe Very problem Severe	Nothing needed at this time Provide written information Talk with a member of the team
Providing care for someone else	1 2 3 4 5 Not a Mild Moderate Severe Very problem Severe	Nothing needed at this time Provide written information Talk with a member of the team
Tobacco Use	1 2 3 4 5 Not a Mild Moderate Severe Very problem Severe	Nothing needed at this time Provide written information Talk with a member of the team
Understanding the importance of physical activity even during treatment	1 2 3 4 5 Not a Mild Moderate Severe Very problem Severe	Nothing needed at this time Provide written information Talk with a member of the team
Talking with the health care team about use of food/herbal supplements while on treatment	1 2 3 4 5 Not a Mild Moderate Severe Very problem Severe	Nothing needed at this time Provide written information Talk with a member of the team
Finding reliable information about complementary or alternative practices (e.g. yoga, medication, message)	1 2 3 4 5 Not a Mild Moderate Severe Very problem	Nothing needed at this time Provide written information Talk with a member of the team

5. References

¹ McLachlan SA, Allenby A, Matthews J, *et al.* Randomized Trial of Coordinated Psychosocial Interventions Based on Patient Self-Assessments Versus Standard Care to Improve the Psychosocial Functioning of Patients With Cancer. Journal of Clinical Oncology 2001; 19: 4117-4125.

- ³ Taenzer PB, Bultz BD, Carlson L, *et al.* Impact of computerized quality of life screening on physician behavior and patient satisfaction in lung cancer patients. Psycho-Oncology 2000; 9: 203-213.
- ⁴ Taenzer PA, Speca M, Atkinson MJ, *et al.* Computerized quality of life screening in an oncology clinic. Cancer Practice 1997; 5: 168-175.
- ⁵ Newell SG, Sanson-Fisher R, Stewart J. Are touchscreen computer surveys acceptable to medical oncology patients? Journal of Psychosocial Oncology 1997; 15: 37-46.
- ⁶ Allenby A, Matthews J, Beresford J, McLachlan SA. The application of computer touch screen technology in screening for psychosocial distress in an ambulatory oncology setting. European Journal of Cancer Care 2002; 11: 245-253.
- ⁷ Holzner B, Zabernigg A, Kemmler G, *et al.* Computerized assessment of quality of life in patients undergoing chemotherapy. Quality of Life Research 2004; 13(9).
- ⁸Cella DF. Methods and problems in measuring quality of life. Support Care Cancer 1995; 3: 11-22.
- ⁹ Drummond HE, Ghosh S, Ferguson A, et al: Electronic quality of life questionnaires: A comparison of pen-based electronic questionnaires with conventional paper in a gastrointestinal study. Quality of Life Research 1995; 4: 21-26.
- ¹⁰ NCCN: Distress: Treatment Guidelines for Patients, ed II. National Comprehensive Cancer Network and the American Cancer Society, 2005.
- ¹¹ Hoffman BM, Zevon MA, D'Arrigo MC *et al.* Screening for distress in cancer patients: The NCCN rapid-screening measure. Psycho-Oncology 2004; 13: 792-799.

- ¹² Sellick SM, Edwardson AD. Screening new cancer patients for psychological distress using the hospital anxiety and depression scale. Psycho-Oncology 2007; 16: 534-42.
- ¹³Zabora J, BrintzenhofeSzoc K, Jacobsen P, *et al.* A new psychosocial screening instrument for use with cancer patients. Psychosomatics 2001; 42: 241-246.
- ¹⁴ Bultz BD, Carlson BD. Emotional Distress: The Sixth Vital Sign in Cancer Care. Journal of Clinical Oncology 2005; 23: 6440-6441.
- ¹⁵Holland JC, Bultz BD. The NCCN Guideline for Distress Management: Case for making distress the 6th vital sign. Journal of National Comprehensive Cancer Network 2007; 5: 3-7.
- ¹⁶Zabora JR, Loscalzo MJ, Weber J. Managing complications in cancer: Identifying and responding to the patient's perspective. Seminars Oncology Nursing 2003; 19: 1-9.
- ¹⁷ Loscalzo MJ, Clark KL. Oncofertility: Fertility Preservation for Cancer Survivors:(Cancer Treatment and Research). Springer Press. 2007.
- ¹⁸ Loscalzo MJ, Clark KL. Problem-Related Distress in Cancer Patients Drives Requests for Help: A Prospective Study. Oncology 2007; 21: 1133-1138.
- ¹⁹ Clark KL, Bardwell WA, Arsenault T, DeTeresa R, Loscalzo MJ. 2009. Implementing Touch Screen Technology to Enhance Recognition of Distress. Psycho-Oncology, 18: 822-830.
- ²⁰ Carlson, LE and Bultz, BD (2003). "Benefits of Psychosocial Oncology Care: Improved Quality of Life and Medical Cost Offset." Health Qual Life Outcomes 1(1): 8.
- ²¹ Thomas, BC; Thomas, I; Nandamohan, V; Nair, MK and Pandey, M (2008). "Screening for Distress Can Predict Loss of Follow-up and Treatment in Cancer Patients: Results of Development and Validation of the Distress Inventory for Cancer Version 2." *Psychooncology*.
- ²² Kelly, C; Ghazi, F and Caldwell, K (2002). "Psychological Distress of Cancer and Clinical Trial Participation: A Review of the Literature." *Eur J Cancer Care (Engl)* **11**(1): 6-15.

² Velikova G, Wright EP, Smith AB, *et al.*Automated collection of quality of life data: A comparison of paper and computer touch screen questionnaires. Journal of Clinical Oncology 1999; 17: 998-1007.