Published in final edited form as:

Support Care Cancer. 2013 March ; 21(3): 889–899. doi:10.1007/s00520-012-1603-8.

A theory-based decision aid for patients with cancer: results of feasibility and acceptability testing of DecisionKEYS for cancer

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Abstract

Purpose—Appropriate utilization of treatment is a goal for all patients undergoing cancer treatment. Proper treatment maximizes benefit and limits exposure to unnecessary measures. This report describes findings of the feasibility and acceptability of implementing a short, clinic-based decision aid and presents an in-depth clinical profile of the participants.

Methods—This descriptive study used a prospective, quantitative approach to obtain the feasibility and acceptability of a decision aid (*DecisionKEYS for Balancing Choices*) for use in clinical settings. It combined results of trials of patients with three different common malignancies. All groups used the same decision aid series. Participants included 80 patients with solid tumors (22 with newly diagnosed breast cancer, 19 with advanced prostate cancer, and 39 with advanced lung cancer) and their 80 supporters as well as their physicians and nurses, for a total of 160 participants and 10 health professionals.

Results—The decision aid was highly acceptable to patient and supporter participants in all diagnostic groups. It was feasible for use in clinic settings; the overall value was rated highly. Of six physicians, all found the interactive format with the help of the nurse as feasible and acceptable. Nurses also rated the decision aid favorably.

Conflict of interest

The authors do not have any conflicts to disclose.

Conclusions—This intervention provides the opportunity to enhance decision making about cancer treatment and warrants further study including larger and more diverse groups. Strengths of the study included a theoretical grounding, feasibility testing of a practical clinic-based intervention, and summative evaluation of acceptability of the intervention by patient and supporter pairs. Further research also is needed to test the effectiveness of the decision aid in diverse clinical settings and to determine if this intervention can decrease overall costs.

Keywords

Solid tumors; Decision aid; Janis and Mann conflict theory of decision making; DecisionKEYS

Introduction

Appropriate utilization of treatment is a goal for all patients undergoing cancer treatment. Proper treatment maximizes the chance of benefit and limits exposure to the risks of unnecessary measures. To accomplish this goal, the treating team needs to be aware of therapeutic options and must communicate sufficiently with the patient to understand his or her goals and preferences based on lifelong values. Decision making in patients with advanced cancer can be difficult in that losses exist no matter which alternative is chosen, and this can lead to patient and family regret [1, 2]. Helping patients and families with the process of making treatment decisions is challenging as time to absorb information or discuss preferences is limited in clinic settings. Nonetheless, engaging in an informed, shared decision making process to reduce decisional conflict can set the stage for more positive outcomes and less ultimate regret. A thorough discussion based on informed decision making at the outset of treatment and at times of therapeutic changes can provide benefits which are an appropriate and economical use of time.

Patients are concerned about decision making. A recent survey of 3,728 patients with cancer and caregivers asked them to rate 26 concerning issues of support related to their cancer [3]. Over 91 % of these individuals rated “making decisions about care” in the top categories (rating this issue as “very important” or “important”). Among the 233 patients with lung cancer, decision making ranked third of the 26 issues; it ranked fourth among the 1,606 patients with breast cancer. These findings illustrate the need to incorporate informed, shared decision making in clinical oncology practice.

Decisional conflict during cancer treatment is frequent. *Decisional conflict* is the “... simultaneous opposing tendencies within the individual to accept and reject a given course of action” [1, p. 46]. Cancer-related decisions can be difficult due to communicating complex and threatening information about prognosis and treatment options [4]. Physicians must use their best judgment in advising further treatment (accounting for such factors as patient factors, performance status, prior response to therapy, and national guidelines for treatment). With the physician’s complicated role as therapist, advisor, and advocate for the patient, physicians may find it difficult to present clearly treatment options and recommendations, particularly when the decision involves such issues as stopping therapy. This is a common situation in which the goal is to help communication between physician and patient in arriving at a shared decision and easing any conflict.

There is also a need to reduce patient misunderstanding and regret related to treatment decisions. A study of 917 patients with advanced cancer found that individuals typically overestimated their 6-month survival probability and this influenced preferences for therapy [5]. Patients who knew they had at least a 10 % chance of not surviving 6 months had different treatment preferences from those who did not know their survival chances. In another example, regret related to treatment decision was substantial (23 %) in a study of

201 men with metastatic prostate cancer, which may derive from underlying stress and problematic communication with physicians [6]. These findings suggest that better information can assist patients in making informed choices in line with their values.

Family influence is one of the many factors affecting a patient's preference for treatment [7]. Most individuals faced with difficult decisions discuss their preference with people whom they expect to support their decision [1, 2]. Such supporters may even replace patients as proxies in interactions with physicians. Patients and their caregivers may differ in their prognostic awareness; uncertainty may be greater in patients than their caregivers [8]. Additionally, patients and their caregivers may disagree about consequential decisions and even the process of decision making [9]. An example of conflict in decision making can occur when the physician unexpectedly and rapidly recommends switching from treatment to discontinuation of therapy, but the patient or family resist [10].

Based on the need for better decision making to help overcome the issues outlined above, the use of decision aids has been proposed. A group called the International Patient Decision Aids Standards Collaboration (IPDAS) has defined a decision aid as an evidence-based tool designed to prepare patients and families to participate in making difficult choices among options [11]. In 2006, a consensus was reached within a large panel of invited experts (over 200) that 74 of 83 of the IPDAS criteria be retained [12]. The question of patient decision aids as the best way to improve clinical decision making was debated in 2007, with approximately half attending a symposium in support [11].

In the more than 200 decision aids registered in the Cochrane Decision Aid Library Inventory, few target patients with advanced cancer. In a 2009 systematic review and meta-analysis, decision aids were found to be effective for cancer screening; however, further research was recommended in the prevention and treatment context [4]. A meta-analysis of 55 randomized clinical trials (RCTs) for patient decision aids indicated that increased patient knowledge, decreased decisional conflict, and increased choices congruent with patients' values are all key outcomes for decision aids [13]. A subgroup of this meta-analysis with 23 RCTs examined decision aids for cancer-related screening and treatment; in this meta-analysis, only five studies were related to decisions of chemotherapy and surgery for patients with a diagnosis of cancer [14]. This meta-analysis postulated that utilization of patient decision aids may reduce overuse of inappropriate interventions.

This current report presents the findings of the preliminary testing related to feasibility and acceptability of implementing short, clinic-based decision aids for patients with cancer (and their chosen support person) developed in 2005 and tested as a series called DecisionKEYS along with a description of the presenting clinical profile of the participants. These findings should help with the design of future studies.

Patients and methods

Study design and setting

This study used a prospective approach to obtain the feasibility and acceptability of a decision aid for the clinic setting by combining the results of three similar trials in different malignancies, all using the same decision aid series and procedures. The participants included patients with solid tumors (newly diagnosed breast cancer, advanced prostate cancer, and advanced lung cancer) and their chosen supporters as part of a pair. Health professionals delivered the decision aid. The study interval was set by typical timing around difficult decisions related to cancer-directed treatment. The study was conducted in outpatient clinics at two universities designated as National Cancer Institute cancer centers. In this initial phase of testing, *feasibility* was defined and measured as the amount of time

for the process and *acceptability* was defined as such and measured by completion of an evaluation form by patients, supporter, nurses, and physicians, in preparation for a clinical trial to more formally measure outcomes. Qualitative results for patient and supporter from taped exit interviews are reported elsewhere by Jones et al. [15].

Intervention

The overall goal of the decision aid intervention, “Decision-KEYS for Balancing Choices: Cancer Care,” is to improve quality decision making for patients dealing with cancer using an informed, shared decision making process. The intent is to improve decision making when there are complex and stressful choices, help with a specific decision, and provide structured time for support by health care providers for difficult decision making as a means of reducing decisional conflict and regret. The decision aid intervention is based on the Janis and Mann conflict theory of decision making [1, 2]. This theory predicts decision making behavior for consequential decisions—those which are emotionally laden and motivationally driven in which perceived losses exist no matter which alternative is chosen. According to the theory, three preconditions (the amount of risk from consequences, hope for finding a better solution, and time pressure to make a serious decision) precipitate a degree of stress, thus affecting the type of decision making style an individual tends to use (Fig. 1). The most effective range of stress is the intermediate range (too little or too much reduces adherence to quality decision making procedures). The decision making style chosen ultimately leads to quality or non-quality decision making and decision satisfaction or regret.

It is proposed that taking patients and their supporter (if available) to a higher level of awareness of quality decision making—not just focusing on the content of decisions as other decision aids do but helping them understand “why” quality decision making is needed (based on learning the premises of the decisional conflict theory from a brief tutorial)—may make them more comfortable with decisions throughout cancer-directed treatment and for palliative care decisions. With emphasis on the preconditions of risk, hope, and time by oncology professionals (in the form of guidance through a tutorial and several different applications of the theory as boosters), more time for clarifying options, values, and preference (through use of a balance sheet), and more time for support (more structured time by the providers), that patients and their supporter will recognize they did their best in following a quality decision making process and will be less likely to feel regret or to dwell on decisions out of their control. They will be more likely to believe they have given their treatment decisions their “best shot” and feel more accepting of the decision outcomes. Thus, if patients and their supporters feel less regret with the decisions made, they can move forward with other palliative care and end-of-life issues, and spend the time they have left in the manner of their choosing.

This decision aid series includes common decisions related to care for each of the cancers, such as type of breast surgery and changing chemotherapy (Table 1). Developed in 2005, the objectives of the series as a comprehensive decision skills program are that it (a) teaches or reviews a psychological theory related to quality decision making as an easy-recall method during decision situations, (b) provides application of the theory using a decisional balance sheet for values clarification related to their cancer treatment options, and (c) provides information about the cancer or treatment. Unique features of this decision aid include the presentation of the theory to the patient, values clarification in regards to treatment, inclusion of the effect of the decision on both self and others, and as a means of helping to determine a decision preference. The components of this decision aid, using a process-oriented approach, are included in Table 2. The tutorial diagram related to quality decision making is presented to the patient/supporter pair (Fig. 1). Components of each decisional balance sheet were developed by the first two authors and consensus derived by two panels of experts (one for decision making, one for cancer-related content). Each decision is

presented as a four-cell balance sheet of positives and negatives key categories of how they may affect the patient and how they might affect others; such a format allows for rapidly changing treatment options to be updated verbally by the physician. These key categories are personalized by the physician but reinforced by the nurse as needed (such as side effects of treatment). The authors used the balance sheet format by Janis and Mann and then developed the content within each balance sheet, followed by validation by a panel of experts, including the theorist, Dr. Leon Mann of the University of Melbourne, who also helped with which parts of the underpinning theory were pertinent for patients with cancer.

Steps of the decisional balance sheet interactive process include the following (total time=~35 min):

- Physician interaction (~5 min) with patient (pair) to present treatment options to consider, specifically “personalized” options, based on the physician’s judgment of expected mortality and quality of life in addition to national guidelines, are presented to the patient. The physician introduces the nurse, who is present, and her role in the process.
- Nurse interaction (~25 min) with the patient (pair) includes time to (1) review the conflict decision theory diagram as a component of the intervention; (2) complete the first decisional balance sheet interactive session of weighing alternatives and clarifying beliefs/values; (3) help the pair add the benefits and risks to determine what decision they are leaning toward (preference), and note concerns/conflicts; and (4) provide additional time for the pair to process the information provided by the physician, further discuss QL-PRO assessment and health-related values, and raise concerns.
- Nurse interaction (~1 min) to provide information to the physician regarding remaining concerns about treatment options and the decision/preference the patient (pair) is leaning toward.
- Physician interaction (~4 min) uses these sources of information from the nurse to enhance this informed, shared decision making process, answer further questions, and then assures that the treatment decision is acceptable to the patient (pair).

To describe the process further, the patient (pair) has time to ask initial questions, but frequently, patients say to nurses, “I didn’t want to bother the doctor, but...” This method gives the patient/supporter pair time to further process the information from the physician and time to consider their own values (values clarification), followed by time to ask the nurse any further questions before deciding on what preference the patient (pair) are leaning toward. The nurse then summarizes the patient’s preference and remaining concerns for the physician. The physician then addresses these concerns and any others from the patient/supporter pair at that time as well as assures that the treatment decision is acceptable to the patient (pair). In summary, the physician interacts in the beginning and again in the end for that session. The intent is a “shared” interactive process—not assent; disagreement generally does not happen in a “shared” process.

Participants

Participants included 80 patients with solid tumors (22 with newly diagnosed breast cancer, 19 with advanced prostate cancer, and 39 with advanced lung cancer) and their 80 supporters, for a total of 160 participants. Additionally, ten physicians and nurses caring for these patients were involved. Inclusion criteria for the subjects were: (1) pathologically or cytologically determined breast, prostate, or lung cancer; (2) age ≥ 18 years; (3) patient and supporter ability to understand English; and (4) participation of a “*supporter*” (a family member or concerned person consistently providing emotional support). Based on the Janis

and Mann theory of decision making, most people faced with a difficult decision will discuss it first with people whom they expect to support their decision [1, 2].

Additional inclusion criteria were disease specific. For patients with breast cancer, the ratio of the tumor to breast size had to be acceptable for the possibility of breast conserving surgery. Patients with lung cancer and brain metastases had to be at least 3 weeks since brain irradiation with stable clinical parameters. An exclusion criterion was documented severe psychiatric problems which could prevent full study participation.

Instruments

A battery of measures with good psychometric properties was used for background information. A medical record review form captured disease history; patients and supporters completed demographic forms.

State-Trait Anxiety Inventory (STAI) is a two-part self-administered questionnaire measuring two aspects of anxiety, state (S-anxiety) and trait (T-anxiety). *Situational distress* is a current emotional state characterized by tension, apprehension, nervousness, worry, and arousal of the autonomic nervous system [16]. The 20-item S-anxiety form was used to gain information on the respondent's feelings at this moment or the distress of the immediate situation. The weighted scores of 1–4 for each item are summed with a score range of 20–80; the higher the score, the more current anxiety. The mean S-anxiety scores are presented in the manual for working adults ages 50–69.

Decisional Conflict Scale (DCS) measures perceived difficulty in making decisions [17]. The DCS has five subscales (informed, values clarity, support, uncertainty, and effective decision). The generic 16-item form was used, with statements like “I am sure what to do in this decision.” The scale uses a 1–5 scale, with the mean score used to rate the degree of decisional conflict. Scores range from 0 (no decisional conflict) to 100 (extremely high decisional conflict).

Decision Making Quality Scale (DMQS) is a seven-item Likert-type rating scale that assesses the degree to which a person adheres to seven quality decision making criteria [18]. Hollen adapted Janis and Mann's [1, 2] seven criteria as: (1) searches for three or more choices, (2) takes into account values and goals desired, (3) weighs the pros and cons of consequences, (4) finds more information about the pros and cons when needed, (5) thinks about new information and what experts say, even if against the first choice, (6) reviews choices carefully before making a final choice, and (7) makes detailed plans with backup plans. The DMQS asks, “How true do you think these statements are about your decision making for important choices (not everyday ones)?” The scale uses a four-point scale (not at all true = 0, very true = 3). The total score was used with a range of 0–21. A cutoff score of 15 represents *high* quality decision making.

Participant Evaluation Forms captured feasibility of delivery (e.g., ease in reading and time in minutes) and overall acceptability (e.g., acceptable time to complete, value of decision aid components, value as a communication aid, and value during treatment) after each decision. A four-point scale was used (not at all true = 0, very true = 3). The frequencies and percents for scores of “somewhat true” and “very true” were combined for each item.

Study procedures

Approval was obtained from Human Investigations Committees at each site. The physician briefly described the study and obtained interest in participation. Written informed consent was obtained from each participant by the study nurse who also administered the battery of measures. The interactive decision process was used with a decisional balance sheet for each

treatment decision. At the last clinic visit, the study nurse set up a follow-up telephone call to the patient and supporter in 1–2 weeks for study closure.

Data analysis

This study used descriptive statistics for the baseline characteristics and perceptions of acceptability of the decision aid as a part of seeking treatment. Baseline comparison of presenting clinical profile factors (anxiety level, decisional conflict, and decision making quality) between the patients and supporters were analyzed by paired *t* tests. Pairs were excluded from individual factor comparisons if one or both did not have a total score for the factor being compared. Following the STAI rule for missing data stated in the manual, one or two items missing were imputed with the mean for all measures; those with more than two items missing were omitted from the analysis of STAI. A similar rule was used for DCS with the number missing being limited to one item.

Results

Presenting clinical profiles

Aims of this study were to outline presenting factors of these patients with cancer and their supporters and to describe a presenting clinical profile of the patients and their supporters who were facing difficult decisions. Anxiety level as well as degree of decision conflict and uncertainty may help with hypothesis generation for future studies, particularly those examining antecedent factors affecting quality decision making as proposed by the underpinning theory. The demographic characteristics of the 160 participants were typical for these diagnostic groups of cancers (Table 3).

Of the newly diagnosed patients with breast cancer and their supporters, patients presented clinically with significantly higher anxiety than their supporters at baseline (Table 4). The *s*-anxiety score was high for patients, but high for their supporters, compared to the average norms for working women ages 50–69 years [16]. There was no significant difference in decisional conflict between patients and their supporters. Decisional conflict scores were low for patients and supporters. Uncertainty subscale scores were moderate for patients, but low for supporters, and these were significantly different. Patients reported significantly higher decision making quality than their supporters, but the mean decision making quality score for patients and for supporters both met the cutoff score for high quality decision making.

A presenting clinical profile for the patients with advanced prostate cancer and their supporters was considerably different from this breast cancer sample (Table 4). The *s*-anxiety score was high for both the patients and their supporters, compared to the average norms for working men ages 50–69 years [16]. There was no significant difference in *s*-anxiety between the patients and their supporters. There was no significant difference in decisional conflict between patients and their supporters. Decisional conflict scores were low for both patients and supporters and similarly for the uncertainty subscale scores. The decision making quality score was high for both patients and supporters; both scores met the cutoff score for high quality decision making.

Table 4 presents the profile of the patients with advanced lung cancer and their supporters. These patients and their supporters were highly anxious at baseline, compared to the average norms for working men ages 50–69 years [16]. There was no significant difference in *s*-anxiety between the patients and supporters. Decisional conflict scores were low for both patients and supporters as were uncertainty subscale scores. There was no significant difference in decisional conflict or uncertainty between patients and their supporters. The

decision making quality scores were high for both patients and supporters; both met the cutoff score for high quality decision making.

Feasibility and acceptability of decision aid

Patients and supporters for each cancer type evaluated the decision aid highly, using ratings of “somewhat true” and “very true” (out of four categories) combined for at least one decisional balance sheet interactive session (Table 5). All three diagnostic groups (newly diagnosed breast cancer, advanced prostate cancer, and advanced lung cancer) rated the decision aid as feasible for use in a clinic (needed <3 min to learn, 64–83 %; easy to use, 100 %; and time acceptable, 92–100 %). Patients rated it highly as a communication/decision aid (decision guide (theory) was a helpful review of quality decision making, 100 %; helped sort through information, 83–100 %; and helped weighing treatment choices with the doctor, 83–100 %). Patients reported that the decision aid helped in discussing treatment with their supporter (75–100 %) and helped them feel they shared in the decision process (63–100 %). Supporters were slightly less positive but accepting overall. Patients’ goals and preferences derived from the decisional balance sheets are reported elsewhere [15].

Of six physicians participating in this study, all found the interactive format as feasible and acceptable in a busy clinic setting. This feasibility was in the context of having the help of a nurse who led the interactive process for the decisional balance sheet. All four oncology nurses serving as study nurses found the process to be a viable role for nurses in addition to traditional roles such as helping with symptom management.

Discussion

This paper presents the feasibility and acceptability testing of an informed, shared decision making process for difficult decisions by using a series of decision aids provided by interprofessional collaboration. The decision aids studied in this trial were found to be acceptable to patients and their supporters and feasible for use in busy clinics. Its overall value was rated highly by all diagnostic groups. In general, patients gave higher ratings than supporters. Physicians and nurses in the clinic settings also found it feasible and acceptable.

This decision aid included a supporter as a participant. Based on the underpinning theory, quality decisions are not made in isolation [1, 2] and most patients reported the decision aid helped in discussing treatment choices with their spouse or support person. In a study of 211 patients with lung cancer (late stage, 54 %), supporters were identified by 67 % of the patients; 83 % were women, 75 % were the patient’s spouse [19]. Inclusion of a supporter adds little to administration time since the interactive process is conducted with the pair.

There were differences in the presenting profiles for these cancer diagnostic groups representing different clinical states in the illness trajectory. All reported high current anxiety and some degree of initial decisional conflict, particularly uncertainty. Using advanced lung cancer as an example, this finding is consistent with an Ottawa study of 20 Canadian patients with stage IV non-small cell lung cancer where a significant decline in decision conflict over time was found using a decision aid [20]. In that study, improvements were greatest in the uncertainty subscale (the patient feeling sure what to do), feeling informed (knowing the pros of chemotherapy), and clarity of values (being clear about what was most important to them). In a similar Toronto study, in which 20 patients with metastatic NSCLC were not considered anxious (median score 29; range 21–43) at baseline, the s-anxiety scores significantly decreased after receiving a decision aid and knowledge significantly improved by 25 %, primarily for prognosis with and without chemotherapy [21]. Although each cancer group in the present study is fairly small, the group with breast cancer reported significant differences in uncertainty between the patients and their

supporters. Decision conflict, particularly uncertainty, appeared to be of most concern for the patients facing difficult treatment decisions.

In the current study, there was variability in the DMQS decision making scores at baseline of the newly diagnosed patients with breast cancer and their supporters, but not for the patients with advanced solid tumors and their supporters. The decision quality scores were higher at baseline than expected. These women and their supporters may have overestimated or “bolstered” their decision making ability to cope with the decision of pending breast surgery or chemotherapy. This possible ceiling effect of the decision making scale could represent a personal bias in response to dealing with the diagnosis of cancer or its treatment and should be reexamined in a future trial according to the decision making theorist [22].

Future studies are needed, as the long-term goal is to provide decision aids to enhance daily practice. These results support conducting studies investigating more cultural diversity and expanding on the feasibility of implementing the program in diverse practice settings. For this study, time involved was part of the definition of feasibility, one often used in establishing initial psychometric properties. A key finding in this study was the feasibility of using a decision aid in a busy clinical setting, as supported by patients, supporters, nurses, and physicians. Yet, there are several limitations concerning the feasibility of this intervention for clinical practice, particularly in relation to the time involved for the decisional balance sheet interactive process. Study nurses reported that the majority of patient (pairs) needed less than 3 min to learn to use the decisional balance sheet, but the full interactive process takes about a half hour. In this study, study nurses supplemented the role of clinical nurses for these patients and were encouraged to refer symptom monitoring to the clinical nurse; however, both roles can be undertaken by the clinical oncology nurse to reduce costs. Indeed, time is needed for monitoring symptoms, but it is only one aspect of supportive care; oncology nurses can help with difficult decisions as well. It is the belief of these authors that nurses can also help support difficult decision making and the gap when patients feel they do not want to “bother” the physician and they want to be “good” patients. The perception of many patients is that physicians are busy, but nurses are less so. If having someone listen to what they value and help them through the decision process is the goal, the outcomes from these patient/supporter pairs provide initial evidence that this hypothesis is true using a decision aid during difficult decisions. Cost savings may occur over time. That is, a thorough process such as this at the outset may save time in future visits, but this hypothesis will need to be tested prospectively.

A second key finding in this study was the acceptability of using a decision aid in a busy clinical setting, as supported by patients, supporters, nurses, and physicians. As with any evaluation survey, the authors recognize that social desirability may have been present on the part of patients or supporters in terms of acceptability; however, taped exit interviews reported elsewhere validated that patients provided fairly accurate information [15]. Also, accrual into this study was slower than expected. Perhaps this indicates a reluctance for the process. This may be related to time for the battery of measures and travel distance (in the catchment area, 60 % typically travel more than 2 h one way). It cannot be determined from this trial whether the slow accrual rate was due to the decision making concept or to participation in a clinical trial. These and other possible limitations should be explored in future experiences if decision aids with their potential benefits are to be incorporated into common daily practice.

This decision aid provided an opportunity for oncology professionals working collaboratively to enhance communication related to difficult decision making for patients with some of the most frequently occurring solid tumors and their supporters during cancer treatment. Utilizing the decision aid in a busy clinic was feasible and the majority of

participants reported that this theory-based decision aid helped them with many aspects of decision making related to their treatment choices for cancer. These findings provide initial results for decision aids in three major malignancies for use by patients and supporters in future trials. Treatment decision making is a complex process involving many antecedent factors including lifelong values and preferences, degree of current stress or anxiety, and decision making style [1, 2]. Whether deemed as preference-sensitive decision making or informed, shared decision making, enhanced communication related to the decision making process from health professionals increases the likelihood of meeting both patients' goals and preferences as well as quality standards [23]. In 2012, changing health care in the USA demands better utilization of the health care team during complex and time-consuming care in terms of costs.

Acknowledgments

We would like to acknowledge that Drs. Hollen, Gralla, and Weiss's lung study was supported by a grant from NIH (National Institute of Nursing Research—1R21NR009346-01A1). Drs. Hollen, Brenin, and Schroen's breast study was supported by a grant from the University of Virginia Cancer Center (National Cancer Institute—P30CA44579) and Women's Four Miler Breast Care Program Award. Lastly, Drs. Jones, Thomas, and Hollen's prostate study was supported by a grant from NIH (National Cancer Institute—1R21CA131754-01).

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Fig. 1.
Diagram of theory adapted for brief tutorial

Table 1

Current series of adult decision balance sheets for cancer care

DecisionKEYS for balancing choices: cancer care			
No.	Title of decision balance sheet	Population	Description
#1	Telling others	All cancer types	Disclosing health status
#2	Starting chemotherapy	Prostate cancer	Hormone-refractory prostate cancer
#3	Starting anti-cancer treatment	Solid tumors	Radiation, chemotherapy, or both
#4	Changing anti-cancer treatment	Solid tumors	Radiation, chemotherapy, or both
#5	Stopping anti-cancer treatment	Solid tumors	Radiation, chemotherapy, or both
#6	Hospice considerations	All cancer types	Generic
#7	Advance directive	All types of disease	Generic
#8	Type of breast surgery	Breast cancer	Breast preservation (or limited surgery + radiation) and mastectomy (or complete removal)
#9	Adjuvant breast therapy	Breast cancer	Chemotherapy, hormone therapy, or both after breast surgery
#10	Future decision	All types	Blank sheet for future decisions once learned process

Table 2

Key components of a decision aid for adults with cancer

DecisionKEYS for balancing choices: cancer care		
Component	Content elements	Process
Social support	Because patients generally do not make decisions in isolation, each patient is asked to choose a <i>supporter</i> (defined as any family member or concerned other who consistently provides emotional support) to accompany the patient to the clinic visits and participate in the decision process with the patient.	Ongoing inclusion of a support person throughout the process if available.
Anticipatory guidance related to the disease and treatment	Includes <i>standard/usual care</i> at the site (e.g., what to do about treatment side effects, signs of an infection, how quality of life is measured, why a treatment would be changed or stopped) using the clinics' existing <i>patient education pamphlets</i> , such as those developed by the National Cancer Institute or Cancer Care National Office.	Content elements have been reviewed by a panel of experts for each type of cancer of interest. The brochures are helpful, but not the primary source of information, which rests with the physician.
A brief quality decision making process tutorial	Teaches parts of a psychological theory in the form of a "Decision Making Guide" (a synopsis of the Janis and Mann's decisional conflict theory), to provide understanding of "why" quality decision making is important and how it affects satisfaction/ regret of a consequential decision. The <i>decision theory</i> has been simplified into an <i>easy-recall method</i> by Hollen using a linear graphic diagram.	Handout with graphic depicting the theory is used at clinic visit and then provided to the patient/ supporter pair to also review at home.
Patient's decision participation preference	Determines the patient's preference for level of participation in treatment decision making and shares this preference with the physician as a part of each decision within the intervention.	Control Preference Scale is used at each decision as preference may change over time.
Normalization	Provides the context of what others in similar situations have done, using the "Cancer Survival Toolbox: An Audio Resource Program" (latest edition) [© 2007; National Coalition for Cancer Survivorship, Oncology Nursing Society, Association of Oncology Social Work, and Genentech BioOncology]. The program includes a basic skills set of six topics: (1) communicating, (2) finding information, (3) making decisions, (4) solving problems, (5) negotiating, and (6) standing up for your rights. To ensure a practical intervention, the overview is used.	CD Toolkit and CD player are in CD Home Kit for the patient/supporter pair to keep for their own. Each pair is shown how to use the CD player and a checklist is provided that outlines the three CDs for the program and amount of time needed to listen to each one.
Values clarification and preference discussion with several difficult decisions during treatment	Uses a <i>decision balance sheet</i> (a summary report for values/concerns/ conflict designed by Janis and Mann) to weigh in terms of the benefits and risks for oneself and others, resulting in values clarification for the patient and care provider. The balance sheet exercise involves completion of a four-cell table related to the pros and cons for self and others, which was reviewed by two panels of experts (decision making and type of cancer). The final entry is the <i>decision preference</i> .	A balance sheet for the consequential decision is used in an interactive process at the clinic visit.
Structured time with oncology professionals to discuss difficult decisions	To enhance decision making to an <i>informed, shared decision making process</i> , additional time is needed with the oncology professionals (at least 15–30 min of additional time with the oncology nurse at each decision time point, and 5 min of additional structured time with the oncologist).	Physician presents initial treatment choices to the patient (pair); nurse helps the patient (pair) process the information using the decision balance sheet; physician then uses information from the nurse to enhance the decision making process and answer further questions; physician then assures that the treatment decision is acceptable to the patient (pair).

Table 3
Presenting clinical profiles of patients/supporter pairs facing difficult decisions related to cancer

Characteristics	Newly diagnosed breast cancer (n=44 participants)		Advanced prostate cancer (n=19)		Advanced lung cancer (n=38 participants)		Advanced lung cancer (n=78 participants)	
	Patients (n=22)	Supporters (n=22)	Patients (n=19)	Supporters (n=19)	Patients (n=19)	Supporters (n=19)	Patients (n=39)	Supporters (n=39)
Age	55 (median)	55 (median)	72 (median)	60 (median)	62 (median)	56 (median)	62 (median)	56 (median)
Gender	100 % women	68 % men	100 % men	89 % women	62 % men	82 % women	62 % men	82 % women
Married	77 %	91 %	79 %	79 %	77 %	82 %	77 %	82 %
School Years	15 (median)	15 (median)	16 (median)	16 (median)	12 (median)	12 (median)	12 (median)	12 (median)
Completed	8–20 (range)	12–25 (range)	0–22 (range)	12–23 (range)	8–24 (range)	9–22 (range)	8–24 (range)	9–22 (range)
Income (< \$40,000)	23 %	23 %	47 %	37 %	37 %	35 %	37 %	35 %

Table 4

Presenting clinical profiles of patients and their supporters dealing with cancer treatment

Profile factors	Mean (SD)	Mean group difference (95 % CI)	Paired <i>t</i> test <i>p</i> value
Newly diagnosed breast cancer:			
State-Trait Anxiety Index—stress scale (STAI)			
Patients	45.7 (12.5)	9.1	<0.01 *
Supporters	36.5 (11.2)	(3.4, 15.0)	
Decision Conflict Scale (DCS)			
Patients	26.9 (12.9)	0.9	0.81
Supporters	25.4 (13.9)	(−6.7, 8.5)	
Uncertainty subscale of DCS			
Patients	52.9 (26.5)	15.0	0.04 *
Supporters	37.5 (22.7)	(0.9, 29.1)	
Decision Making Quality Scale (DMQS)			
Patients	19.0 (1.8)	1.9	0.04 *
Supporters	17.0 (3.9)	(0.1, 3.6)	
Advanced prostate cancer:			
State-Trait Anxiety Index—stress scale (STAI)			
Patients	37.6 (9.0)	−0.6	0.87
Supporters	38.1 (11.9)	(−7.7, 6.6)	
Decision Conflict Scale (DCS)			
Patients	26.1 (13.8)	−1.6	0.65
Supporters	27.6 (13.6)	(−8.7, 5.6)	
Uncertainty subscale of DCS			
Patients	36.4 (20.5)	−3.1	0.57
Supporters	39.5 (17.3)	(−14.2, 8.1)	
Decision Making Quality Scale (DMQS)			
Patients	16.8 (4.3)	−0.2	0.89
Supporters	17.2 (3.8)	(−2.8, 2.4)	
Advanced lung cancer:			
State-Trait Anxiety Index—stress scale (STAI)			
Patients	40.9 (12.1)	−2.4	0.46
Supporters	42.6 (15.5)	(−9.0, 4.1)	
Decision Conflict Scale (DCS)			
Patients	23.1 (12.3)	−2.3	0.45
Supporters	25.6 (13.6)	(−8.4, 3.8)	
Uncertainty subscale of DCS			
Patients	31.2 (19.8)	−4.2	0.36
Supporters	35.5 (20.3)	(−13.3, 4.9)	
Decision Making Quality Scale (DMQS)			
Patients	16.6 (3.6)	−0.2	0.76
Supporters	16.8 (3.6)	(−1.8, 1.3)	

Mean S-anxiety scores in manual for working adults ages 50–69 (men, 34.51; women, 32.20). Scores range from 0 (no decisional conflict) to 100 (extremely high decisional conflict). Decisional conflict (0 = no conflict; 100 = extremely high); scores at the ties interpreted as possible transition to a higher level. Decision making (15 represents high quality)

*
 $p = 0.05$

Table 5
Evaluation of decision aid by enhanced care participants with a solid tumor diagnosis

Feasibility	Newly diagnosed breast cancer (n=11 pairs ^d)		Advanced prostate cancer (n=19 pairs)		Advanced lung cancer (n=19 pairs)	
	Patients (%)	Supporters (%)	Patients (%)	Supporters (%)	Patients (%)	Supporters (%)
Decisional balance sheets were easy to read.	100	100	92	100	100	100
Decisional balance sheets were easy to use.	100	100	100	91	100	100
Time needed to fill out the balance sheets was acceptable.	100	90	92	91	100	100
Percent of patients needing <3 min to learn to use the decisional balance sheets.	64	60	67	45	83	73
Decision aid components:						
Decision guide (theory) was a helpful review of quality decision making.	100	89	92	70	100	100
Chance to practice with the first "Telling Others" decisional balance sheet was helpful.	100	90	83	64	83	90
Decisional balance sheets were helpful.	100	89	100	89	88	71
Communication aid:						
Decision aid helped me to sort through the amount of information related to my treatment choices in terms of what is important to me	100	89	83	80	100	86
Decision aid helped me be thorough in weighing my treatment choices with my doctor.	100	89	83	70	88	83
Decision aid helped me in speaking with my doctor or nurse about my personal values related to my treatment choices.	100	78	75	80	50	83
Decision aid helped me in discussing my treatment choices with my spouse or support person.	100	78	82	78	75	83
Overall value:						
Decision aid was helpful for arriving at the decisions for my cancer treatment with my doctor.	100	89	80	67	63	83
Decision aid helped me feel that I shared in the decision making for my treatment.	100	78	70	78	63	83

Those with responses of "somewhat true" and "very true" combined

^aSmall randomized study with funding problem