

# Decision making and quality of life in the treatment of cancer: a review

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## Abstract

**Introduction** Complexity in decision making for cancer treatment arises from many factors. When considering how to treat patients, physicians prioritize factors such as stage of disease, patient age, and comorbid illnesses. However, physicians must balance these priorities with the patient's preferences, quality of life, social responsibilities, and fear of uncertainty. Although these factors are important, physicians are often unable to effectively judge their patients' prefer-

ences. Patients are often unable to fully understand their prognoses and the treatment intent.

**Discussion** These differences influence how patients and physicians make treatment-related decisions. Partially due to these differences, patients are initially more likely than their physicians to accept greater risk for lesser benefit from treatment. As time progresses and as they experience treatment, a patient's preference changes, yet little is known about this process since few studies have examined it in a prospective longitudinal manner. We present an overview of the literature related to patient and physician decision making and quality of life in patients with advanced cancer, and we propose approaches to future decision-making models in cancer treatment.

**Keywords** Decision making · Quality of life · Patient-reported outcomes

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## Introduction

Complexity in decision making for cancer treatment arises from many factors. Various treatment options often exist; both oncologists and patients must carefully weigh the risk of treatment-related toxicity versus the potential for benefit as measured by improvement in symptoms, prolonged survival, or disease control. The delicate balance between toxicity and benefit is influenced by other issues permeating the patient's life, including work responsibilities, family commitments, and financial burdens, with additional inputs from culture, social norms, and spirituality [29, 38, 49, 59]. Despite a large body of literature devoted to better understanding the decision-making process in cancer treatment, discrepancies still exist between patients, physicians, and their respective priorities. Knowing that multiple factors

affect the way patients with cancer are treated, what can be done to improve upon current decision-making models to help patients and physicians make more appropriate concordant decisions?

To answer this important question, the following subquestions must first be addressed: (1) which factors are most important to oncologists and patients in determining how to treat cancer? and (2) where do patients and physicians disagree on issues related to treatment? Based on answers to these two questions, how can current decision-making models be improved?

## Materials and methods

The intent of the literature overview was to summarize the available published information. This review was not conducted as a formal systematic review with meta-analysis, as our intent was to provide an overview of factors to incorporate into decision-making models, using available data related to treatment decision making. Two searches were structured in order to address the topics of this manuscript, focused for physicians and patients: (1) physician-focused topic: what are the factors contributing to physician decision making in cancer treatment and (2) patient-focused topic: what are the known patient preferences that contribute to cancer decision making *and* what is the discordance between physicians and patients? The second topic was a combination of two subtopics since

much of this literature is intertwined. While physician and patient factors were approached as distinct in this review, they are inherently integrated. For example, identified research on physician factors integrated patient preferences since the datasets included treatment choice.

We systematically searched the Medline/Ovid database from 1966 to 2008 for search terms related to each topic (Table 1). We intend to present a unified decision-making model that could be explored in a circumscribable group of patients undergoing repeated treatment decision making across the care continuum. In order to do so, we chose to restrict the search to colorectal cancer whenever possible. Colorectal cancer is an appropriate disease in which to study such a decision-making model due to the multiple stages of treatment-related decision making encountered during the longitudinal care continuum. Hence, we specifically searched for studies related to colorectal cancer, although our general search strategy was more broadly applied to all cancer types especially in terms of patient decision making, where data specific to colorectal cancer were more scant. Since this literature is broad, not clearly summarized, and uses inconsistent terminology, references from included articles were hand searched as a secondary search strategy. When more than one study with identical findings was identified, the highest quality study was chosen for presentation in this review in order to keep the amount of presented information manageable and interpretable.

A total of 411 articles were identified, 246 pertaining to the physician decision-making topic and 165 pertaining to

**Table 1** Inclusion/exclusion criteria and search strategies

Search terms/steps	Number of identified articles
Factors contributing to physician decision making in cancer treatment	
1. Colonic neoplasms.sh.	48678
2. Aged.sh. or age factors.sh. or marital status.sh. or socioeconomic factors.sh.	2,025,564
3. Treatment.mp. or Therapeutics.sh.	2,186,224
4. Cohort studies.sh. or retrospective studies.sh.	378,463
5. Steps 1 and 2 and 3 and 4	317
6. Limit step 5 to (English language and humans and year = "1966–2008" and "all adult (19 plus years)")	246
7. Exclude studies not primarily related to colorectal adenocarcinoma or not related to physician therapeutic decision making	214
8. Final number of articles reviewed	32
Known patient preferences that contribute to cancer decision making <i>and</i> discordance between physicians and patients	
1. Exp neoplasms.sh.	2,001,006
2. Decision making.sh. and quality of life.sh. and Physician–Patient Relations.sh.	159
3. Decision making.sh. and patient satisfaction.sh.	880
4. Steps 2 or 3	1023
5. Steps 1 and 4	237
6. Limit step 5 to (English language and humans and year = "1966–2008" and "all adult (19 plus years)")	165
7. Exclude articles not related to cancer therapy, patient preferences for decision making in cancer treatment, or patient–physician discordance in therapeutic decision-making	102
8. Final number of articles reviewed	63

the patient topic. Articles from the physician decision-making search were excluded for not directly relating to colorectal adenocarcinoma (26%) or physician therapeutic decision making (61%), with 32 remaining. Articles from the patient decision-making/discordance search were excluded for not directly relating to cancer therapy (26%) or not related to patient preferences/patient–physician discordance in decision making (36%), with 63 remaining. Of note, while physician and patient factors were approached as distinct in this review, they are inherently integrated. For example, identified research on physician factors integrate patient preferences since any treatment choice usually assumes patient involvement.

## Review

### Factors contributing to physician decision making in cancer treatment

Tumor and biologic characteristics including stage and presence and location of metastases are usually the primary determinants of how patients with cancer should be treated. Patients with node-positive colorectal cancer or those with fewer lymph nodes resected experience significantly worse survival than those with node-negative disease [6, 33, 63] and thus are more likely to receive adjuvant chemotherapy [41]. Patients who initially present with bowel obstruction have worse survival than those without [46]. Preoperative serum levels of tumor markers such as carcinoembryonic antigen might also assist in identifying poor prognosis patients who might benefit from adjuvant chemotherapy [26]. Such factors are among the first considered by oncologists when determining care for their patients, but other patient characteristics contribute greatly to physician decision making. These characteristics include age, comorbidity, performance status, quality of life, and patient preference.

Age often enters into the decision-making equation. Colorectal cancer serves as a useful disease model in this instance, as the median age at diagnosis of colorectal cancer in the US is 71 years [44]. In 2000, a systematic review of 28 studies aggregated data from over 34,000 patients with colorectal cancer [9]. Patients >85 years old were less likely than younger patients to undergo surgery for their colorectal cancer. When they did undergo surgery, the rates of curative (versus palliative) surgery were significantly lower for the elderly, while rates of emergency surgery were higher. Advanced age has also been associated repeatedly with a decreased likelihood of receiving chemotherapy. A study of 6,959 colorectal cancer patients identified in the Surveillance, Epidemiology, and End Results (SEER)–Medicare linked database demonstrated a significant association

between receipt of chemotherapy and age, where older patients were less likely to receive adjuvant chemotherapy even after adjusting for presence of comorbid conditions [52]. These results have been corroborated by other studies, including a smaller single institution study which showed that elderly patients who had undergone resection for colorectal cancer and were eligible for adjuvant chemotherapy did not receive chemotherapy [37]. An analysis of California Cancer Registry data including 1,956 patients found that patients  $\geq 85$  years were significantly less likely than younger patients to receive adjuvant radiotherapy for their rectal cancers [2]. Similar results from identified from a SEER–Medicare linked database study of 1,670 stage II and III rectal cancer patients: patients  $\geq 85$  years were significantly less likely to receive radiotherapy or chemoradiotherapy even after adjusting for degree of comorbidity [53]. These studies suggest a numerical age bias against treating older patients.

Despite this evident bias, elderly patients who do receive stage-appropriate therapy tend to do as well as their younger counterparts. Goldberg et al. conducted a retrospective pooled analysis of four clinical trials evaluating adjuvant chemotherapy for colorectal cancer [21]. Relative benefit of chemotherapy in terms of response rate and survival did not differ in patients younger or older than 70 years. Only patients healthy enough for clinical trial participation were included, but studies have found similar results in nontrial samples [58]. A single-institution study of 844 patients found that elderly patients with metastatic colorectal cancer did not demonstrate worse toxicity or longer in-patient hospital stays compared to their younger counterparts [47]. From a surgical perspective, older patients have the potential to tolerate surgery as well as their younger counterparts. A recent case–control study demonstrated that while patients >80 years might have shorter long-term survival compared to younger patients, they do not experience worse 30-day mortality or complications [34]. Hence, in order to be a useful tool in decision making, age must not be considered alone but in conjunction with the patient's preference, performance status, and burden of comorbid disease.

The degree of comorbidity impacts various decision-making points along the cancer care continuum. The presence of comorbid illness is rated by physicians as one of the most important issues when considering treatment options [2]. A SEER–Medicare linked database study of 5,330 patients  $\geq 67$  years old with stage III colorectal cancer found that patients with preexisting diabetes, congestive heart failure, or chronic obstructive pulmonary disease were significantly less likely to receive adjuvant chemotherapy [23]. However, those patients with comorbid illness who did receive chemotherapy were just as likely to obtain a survival benefit from treatment. Of note, this study used the

Charlson Comorbidity Index to determine comorbidity status and was thus unable to discern the severity of disease. Another larger retrospective study examined the effect of common chronic conditions on mortality in 29,733 patients with nonmetastatic colorectal cancer in the SEER–Medicare linked database. In this study, the predicted 5-year survival rate for an otherwise healthy early-stage patient was 78%. If the same patient had multiple comorbid conditions, the 5-year survival rate decreased to 50%, which is the same survival rate for a healthy patient with a more advanced cancer stage [22]. Analysis of data from a large cooperative group clinical trial investigating adjuvant colorectal cancer chemotherapy regimens found that patients with diabetes faced a higher rate of cancer recurrence and overall mortality than those without diabetes (after controlling for other predictors of cancer outcome) [40]. Overall, these data suggest that comorbid conditions influence delivery of care and, subsequently, survival, thereby making comorbidity crucial in treatment-related decision making.

Other factors which influence delivery of chemotherapy include patient race and/or socioeconomic status. A SEER–Medicare study of over 18,000 colorectal cancer patients found that lower socioeconomic status (as measured by education level, poverty level, and income) was significantly associated with decreased survival, even after controlling for race and tumor characteristics [14]. Among patients who were seen by a medical oncologist, African-Americans are less likely to receive chemotherapy for colorectal cancer [3]. African-Americans have been shown to be less likely to receive radiation therapy for rectal cancer [2, 13] and surgical resection for colorectal cancer [13]. Marital status, as another marker of socioeconomic status, has also been related to receipt of standard colorectal cancer therapy, such that unmarried patients are less likely to receive adjuvant chemotherapy [2, 48]. The extent to which factors such as race and socioeconomic status play a conscious role in physician decision making regarding treatment is unclear.

#### Known patient preferences that contribute to cancer decision making

One of the most important factors in treatment-related decision making—and one of the most difficult to consistently measure—is patient preference. Even after accounting for stage, age, and comorbidity, a patient might still decline therapy suggested by the oncologist, and this preference-based decision is not easily conveyed through cancer registry data. When patients consider treatment options for their cancer, they rely on information regarding perceived treatment efficacy, quality of life, and proximity to end of life.

As would be expected, patients are generally more willing to accept treatments when those treatments improve chances of survival with minimal toxicity [27, 30, 55, 64]. However, patient decision making is more commonly made with trade-offs between survival and quality of life. A study of 110 patients who had undergone resection for colorectal cancer found that, when presented with hypothetical scenarios, patients were willing to forego chemotherapy and trade potential survival benefit for improvement in quality of life [56]. On the other hand, based on preliminary data among colorectal cancer patients, where over a third of patients surveyed had previously received adjuvant chemotherapy, participants were willing to accept the toxicity of adjuvant chemotherapy for only a 1% recurrence risk reduction [35]. Based on these examples, patients with cancer are understandably grappling with and reacting to uncertainty and may be unable to fully understand the portfolio of available treatment options. Those who have not experienced treatment might opt for preservation of quality of life at the cost of survival benefit or vice versa. Furthermore, it is still unclear how these preferences evolve once people undergo treatment.

Other factors impact patient treatment preference, especially the opinion of their care provider [4, 27, 57]. For patients who receive surgery for colorectal cancer, trust in a surgeon, a surgeon's expertise, and the surgeon's ability to communicate are important to patient decision making [51]. Issues related to home and work life influence how patients make treatment decisions; preferences of the patient's partner or children have been shown to play an important role in patient decision making [57]. Being married and having children impacts preferences [27]. When presented with hypothetical scenarios, patients with children living at home are much more likely than those without children at home to trade quality of life for a survival advantage [64]. In addition, patients living alone are less likely than those living with others to pursue treatment for advanced-stage malignancies [64]. In patients with colorectal cancer, a colorectal cancer diagnosis among family members influences the treatment-related decision process [51].

As cancer patients approach the end of life, their propensity to accept greater treatment-related risk increases, though the transition point where this occurs is unknown. Patients with advanced cancer have a high expectation of treatment benefit, as demonstrated in the phase I clinical trial population. The primary intent of a phase I trial is to determine toxicity and appropriate dosing of experimental therapies, not to assess tumor response. Indeed, objective benefit in phase I trials is historically seen for less than 5% of participants [11]. Regardless, the vast majority of patients enrolled in phase I trials expect a great deal of therapeutic benefit and minimal toxicity, and few participate with a primarily altruistic aim even when fully

informed of the study's intent [8, 11]. Meropol et al. surveyed 328 patients with advanced cancer who were offered enrollment in phase I trials [39]; 19% of these patients had colorectal cancer. A median 60% expected some benefit from the experimental therapy, and 39% expected their best possible outcome to be "totally cured." These results suggest that patients with advanced cancer, including those with colorectal cancer, are willing to take substantial risks in terms of therapy. A better understanding is needed of when in the care continuum risk-taking preferences take priority over quality of life preferences. Importantly, this concept needs to be studied outside of clinical trials because clinical trials are usually restricted to those with excellent performance status, which can bias preferences for treatment.

Many factors—including risk of toxicity, potential for benefit, family influence, quality of life, and prior experience with therapy—are thus involved in the patient's preference for treatment. Attention should be paid to formalizing these patient preferences into the cancer decision-making model. Developing an integrated model could assist in individualizing care based on each patient's priorities.

#### Discordance between physicians and patients

While much is known about what physicians and patients separately consider important when making treatment decisions, given the complexity of issues, the mismatch between physician and patient is not surprising. The literature on this subject has consistently demonstrated discordance in treatment preferences and prognosis between patients and physicians. Cheng et al. surveyed 30 patients with advanced cancers who had chosen to enroll in a phase I clinical trial [8]; 33% had colorectal cancer. The survey obtained perceptions of predicted benefit from treatment. The patients' physicians were also surveyed to assess the physicians' perceptions of benefit from experimental therapy. Patients' mean expectations of benefit from therapy (60%) were significantly higher than those of their physicians (24%). Patients' mean expectations of toxicity (30%) were also significantly higher than those of their physicians (16%). Patients are much more willing than their health care providers to accept greater risk for less benefit, and patients expect more benefit from treatment than their care providers.

Patient preference is also determined, in part, by the patient's own estimate of survival. Patients have consistently overestimated their life expectancy and probabilities of cure when compared to their physicians' estimates. A Canadian study surveyed 100 patients with cancers of varying stages, of which seven had colorectal cancer [36]. Of the 48 patients with advanced cancers who were being

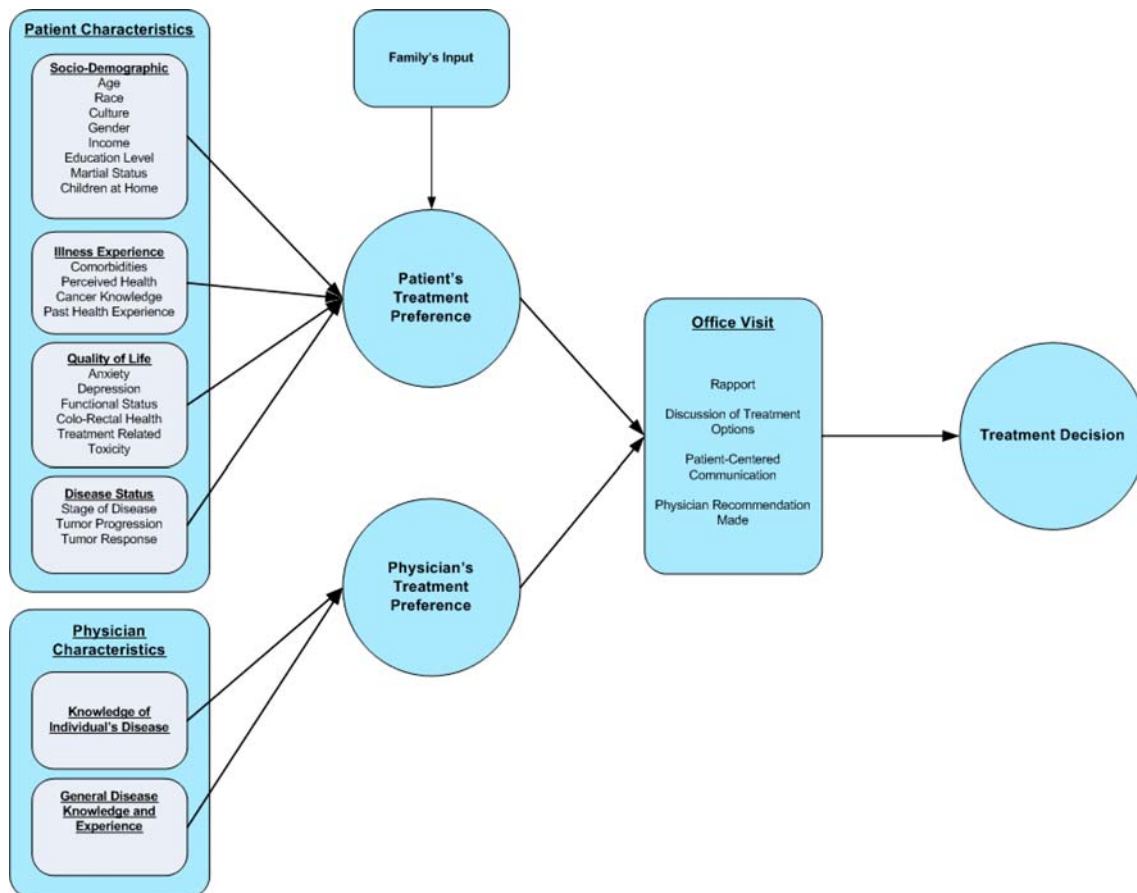
treated palliatively, 16 thought their treatment was of curative intent and 40 significantly overestimated the probability of therapeutic benefit, in comparison to their physicians' estimates. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) was a prospective cohort study of outcomes and decision making in hospitalized patients with serious illnesses, including late-stage lung and colorectal cancer [42, 50]. Patient interview and medical record data were collected in an attempt to better understand associations between patient preferences and practice patterns. Weeks et al., in an analysis of SUPPORT data (39% colorectal patients), found that 82% of patients' survival estimates were more optimistic than physician's estimates [61]. Furthermore, when estimates were compared to actual survival, physicians were significantly more accurate than their patients.

These data bring important and interrelated issues to the forefront of treatment-related decision making: first, patients may be unable to accurately predict their own survival and second, patients may not understand or realize the intent of the treatment they receive. These areas of concern suggest that current models for decision making might result in implementation of inappropriate treatment plans due to considerable discordance between patients and their physicians.

#### Current decision-making models

Based upon this overview of factors which impact cancer care, the current model for cancer treatment decision making appears to be dependent upon factors which influence both physician and patient preference, synthesized in Fig. 1. Generally, physicians are influenced by their overall knowledge of the disease process and their knowledge of the patient before them, including factors such as disease stage, patient age, degree of comorbidity, and possibly socioeconomic status or race. Patient preferences are influenced by perceived treatment efficacy, family preferences, quality of life, and proximity to end of life. Patient and physician influences and preferences should ideally merge to produce a mutually agreed-upon treatment decision.

In a cross-sectional framework, this decision-making model assumes an acceptable balance between the patient and physician in terms of shared decision making. However, one of the greatest obstacles in shared decision making between patients and physicians is in knowing how much involvement a patient wants or needs. Shared decision making seeks the optimal balance by first, ensuring the presentation of information to the patient and second, incorporating both the patient's and physician's values into the final decision [20]. Patients who obtain their



**Fig. 1** Patient and physician treatment decision-making model. Multiple factors are involved in the decision-making process as a treatment plan is developed

optimal level of shared decision making report greater satisfaction with their cancer care [20, 60]. As many studies have shown, patients are heterogeneous in their willingness to participate in the decision-making process [5, 7, 12, 15, 20, 60]. While the current decision-making model is effective, it is limited by frequent imbalance in the degree of shared decision making between patients and physicians.

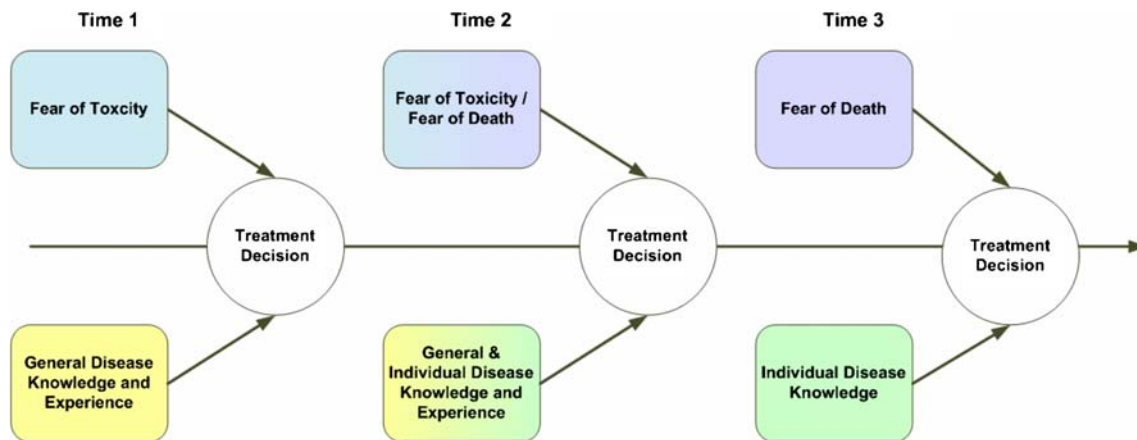
Beyond shared decision-making, patient treatment preferences evolve as patients progress along the cancer trajectory from diagnosis to end of life, though this progression has not been well studied [17]. The change in preferences is likely related to treatment experiences coupled with the impact of the disease and treatment on quality of life. For example, patients unfamiliar with chemotherapy may be most concerned by acute toxic effects like nausea, vomiting, and hair loss, and these concerns are paramount in their initial decisions. As acute toxic effects become less terrifying, the balance of the risk of death or missing a child's high school graduation may be a greater influence than concern about toxicity. Physician treatment preferences might also evolve along the continuum. Physician decisions are based upon a body of knowledge that incorporates general knowledge coupled with patient-specific information. As the patient

progresses along the treatment trajectory, physicians get to know the patient as an individual and may depend more on patient-specific knowledge rather than their general knowledge. Since both patient and physician preferences are changing over time, cross-sectional or infrequent evaluation of patient preference could contribute to inaccurate assumptions on the part of the physician. This inaccurate assumption could negatively impact quality of care, patient satisfaction, and patient quality of life in general. A depiction of the current state of longitudinal decision making is depicted in Fig. 2.

#### Decision-making models for the future

Best shared care decision-making models incorporate patient preferences along the continuum of care, accommodating changes that naturally occur. Recent hypothetical models have been described; the most applicable to cancer care is that of the "dynamic treatment regime."

Dynamic treatment regimes are rules that recommend when and how treatment should change based on prior response to therapy, patient characteristics, and treatment adherence [43]. This model of decision making, initially



**Fig. 2** Patient and physician decision making over time. The *central line* represents the progression of time with multiple points of treatment-related decision making. Above this line, factors important to patients are represented, while *below the line*, factors important to physicians are represented. As patients progress along the treatment

continuum, they are more likely to be influenced by the fear of death than the fear of treatment-related toxicity. As the physician progresses along with the patient, the physician is more likely to depend on the knowledge of the individual patient than on a general body of knowledge

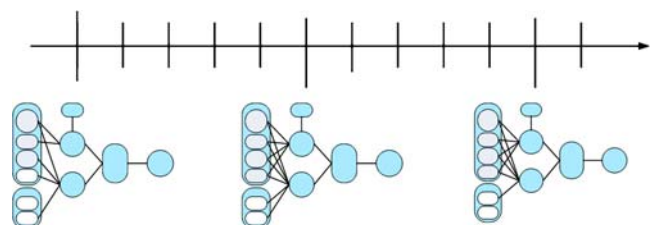
described by Lavori et al. [32], has been previously utilized in the treatment of depression, HIV, and substance abuse [43]. Dynamic treatment regimes incorporate longitudinal reassessment of preference into the treatment algorithm and thereby avoid the pitfalls of the cross-sectional model [31]. Dynamic treatment regimes identify four aspects of decision making that are vital to sequential medical decision making: sequencing critical decision points, outlining treatment options, tailoring variables (such as patient preference, comorbidity, prior treatment, etc.), and specifying a decision rule which presents the optimal treatment option. In short, the assessment and incorporation of patient preferences outlined in Fig. 1 should formally occur at each evaluation (Fig. 3).

Colorectal cancer is an appropriate disease in which to study such a decision-making model due to the multiple stages of treatment-related decision making encountered during the longitudinal care continuum. Patients and physicians begin by considering surgery for localized disease, possibly followed by adjuvant chemotherapy and radiation. Should the disease recur, additional treatments are again considered. Most importantly, patients with advanced colorectal cancer are living approximately 2 years from the time of metastatic recurrence, thereby providing an adequate timeframe in which to evaluate longitudinal changes in decision-making preferences.

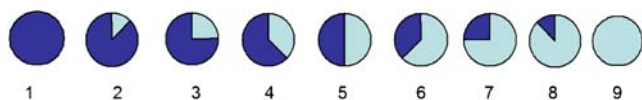
Assessment of dynamic models is currently limited by study design, most notably cross-sectional designs where surveys are conducted prior to, during, or after receiving treatment. When patient preferences are assessed at a single time point, changes in those preferences, as dictated by therapy or changes in health status, are not assessed. If results from such studies are ever to be applied to real-world practice environments, such cross-sectional study

design need to be set aside for a longitudinal approach. Even when quality of life or treatment preferences are assessed at two or three time points, important changes in health states might be missed. Changes might occur before or after the evaluation, or changes in disease states might influence preferences [28, 45]. With repeated measuring of quality of life, a transition point—where the preference for survival exceeds that for preserving quality of life (or vice versa)—might be identified. Understanding where that transition point from valuing quality of life in any degree over survival occurs is vital to helping patients through the shared decision-making process. However, given the large number of variables and scenarios that dynamic models generate, it is hard to imagine its practical application. Computerized assessment systems that incorporate clinical variables, patient reported concerns and preferences, and physician preferences could facilitate integrated insight and act as decision-making tools. Practical synthesized measures that accommodate for the multiple variables and can be assessed repeatedly (e.g., at each clinical visit) can also facilitate insight.

One such synthesized measure is “relative health stock” (RHS). The Health Stock Risk Adjustment (HSRA) model



**Fig. 3** Longitudinal assessment of patient treatment preferences. Decision-making factors should be reassessed  $t$  multiple points along the cancer care trajectory



**Fig. 4** Relative Health Stock pie model. Patients were asked to identify the *portion of the pie* that best represented how much of that fullness had been lost due to the most recent diagnosis or change in condition. Patients were shown *nine pies* with 1/8 incremental changes and scored such that respondents who chose *pie 2* would have an RHS score of 87.5%

was specifically proposed to explain the phenomenon of transition between quality of life-focused to survival-focused care that cancer patients may undergo [18]. Prior to entering a disease state, patients have a baseline health stock, which is the patient's health state including expected longevity and quality of life [24, 62]. According to the HSRA model, a change in health status will affect perceived life expectancy and quality of life, in that as a patient becomes sicker, his health stock decreases [19]. For example, a healthy 65-year-old American man would expect to live out his natural life expectancy of approximately 75 years and would make decisions based on that life expectancy. If that same 65-year-old man were diagnosed with metastatic colorectal cancer, his live expectancy and health stock would decrease significantly as a result of this change in health state. If the change in health stock could be captured prospectively in a decision-making model, physicians would be able to offer care more in line with the patient's expectations.

Indeed, the concept of changing health stock, or relative health stock, has been applied to the oncology population as a measure of patients' sense of loss in their health due to illness. Gaskin et al. conducted a multicenter study involving 328 cancer patients who had been offered participation in phase I trials [19]. The patients were asked to estimate their RHS and the probability of therapeutic benefit from the experimental therapy. To avoid patient anxiety related to eliciting life expectancies, patients were asked to think of the fullness of their life prior to their most recent diagnosis as a whole pie (Fig. 4). They were then asked to identify the portion of the pie that best represented how much of that fullness had been lost due to the most recent diagnosis or change in condition. Patients were shown nine pies with 1/8 incremental changes and scored such that respondents who chose pie 2 would have an RHS of 87.5%. This study found that RHS scores were not related to demographic characteristics. Moderate relationships were observed between RHS and health-related quality of life measures. Most importantly, higher RHS was associated with a decreased likelihood of phase I trial participation. If participation in phase I trials is an acceptable proxy for risk taking in this study, a patient with greater risk-seeking preferences would be expected to have a lower RHS. Hence, if measured longitudinally as a

patient moves along the care continuum from diagnosis to death, RHS might be used to improve treatment-related decision making as patients experience disease progression.

#### Assessing newer decision-making models

Many studies, ranging from small case series to large multicenter cohorts, have attempted to gain insight into the very difficult concept of patient quality of life and decision making in relation to cancer treatment. Due to the financial and logistical hurdles associated with designing such studies as well as anticipated participant burden, they are usually restricted to assessments at one to three time points along the cancer care continuum from diagnosis to end of life. Despite the large body of literature accumulated on this important topic, physicians do not fully understand the needs of their patients, patients do not understand the intent of the treatment or the degree of toxicity they might face, and both patients and physicians are unclear as to how involved the other should be in the decision-making process.

Future studies on patient preference and quality of life should focus on obtaining patient-reported data as he or she moves through each health state. Even though quality of life guides decision making for both patient and physician, quality of life measurement has not gained full acceptance as a clinical tool due to its perceived subjective nature [54]. Yet, this subjective nature of quality of life data stems from the fact that it is reported from the patient and is actually its greatest asset in the realm of decision making [25]. Future studies might avoid hypothetical scenarios and focus on collecting patient-reported data from patients who are actually experiencing the health state in question. Studies should be longitudinal in design. Large clinical trials should be designed to include quality of life assessments as planned end points; for example, recent efficacy trials of cetuximab in head and neck and colorectal cancer successfully collected and reported on quality of life data and its association with survival outcomes [1, 10, 16]. Finally, future studies should focus not only on developing new measures of quality of life but also on validating current feasible measures to ensure clinical applicability in a longitudinal framework.

New decision-making models will need to be developed sequentially due to their complexity. First, the appropriate patient population should be selected for study. To thoroughly test a decision-making system, the population in question might have an advanced cancer with a relatively long life expectancy and multiple treatment options providing points for decision making along the care trajectory. Patients with metastatic colorectal cancer fit well in this model. After selecting an appropriate patient population, the complexity of the model dictates that it is initially addressed in



segments, separating the patient and physician decision-making process. While the two are naturally intertwined in daily practice, separate evaluation of their decision making improves study feasibility; subsequent studies can combine the evaluations. Finally, data can be quickly and reliably collected using wireless computer-based software designed for collecting research-quality data in the clinic setting. This real-time, practical, data collection method allows multiple assessments without undue participant burden. Through a planned stepwise approach, a complete summary of cancer treatment decision making can be sequentially generated without overwhelming both physician and patient. These critical data will contribute to tailoring treatment decisions in the future.

## Conclusions

Complexity in cancer decision making arises from a broad array of factors, including disease characteristics, patient preference, and physician preference. Patients and physicians might not agree on which factors are most important. Based on available data, physicians might not be able to adequately assess the psychosocial needs and treatment preferences of their patients. As a result, new methods should be sought for assessing treatment preferences, prioritizing influential factors, and promoting shared decision making between patients and physicians. Studies designed to understand how treatment-related decisions are made can be burdensome to emotionally overwhelmed patients. Oncologists faced with busy practices might be resistant to sorting through data from such studies to determine how care can be further individualized for their patients. Hence, a stepwise approach to crystallizing the decision-making process is necessary, with an eventual goal of synthesizing patient-reported data into easily digestible information. Armed with a true representation of a patient's preferences, oncologists can deliver care that is concordant with their patient's needs and systems of belief.

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## References

- Au H, Karapetis C, Jonker D, O'Callaghan C, Kennecke H, Shapiro J (2007) Quality of life in patients with advanced colorectal cancer treated with cetuximab: results of the NCIC CTG and AGITG CO.17 trial. *J Clin Oncol* 25:4002 2007 ASCO Annual Meeting Proc
- Ayanian JZ, Zaslavsky AM, Fuchs CS, Guadagnoli E, Creech CM, Cress RD et al (2003) Use of adjuvant chemotherapy and radiation therapy for colorectal cancer in a population-based cohort. *J Clin Oncol* 21:1293–1300 doi:10.1200/JCO.2003.06.178
- Baldwin LM, Dobie SA, Billingsley K, Cai Y, Wright GE, Dominitz JA et al (2005) Explaining black–white differences in receipt of recommended colon cancer treatment. *J Natl Cancer Inst* 97:1211–1220
- Beaver K, Jones D, Susnerwala S, Craven O, Tomlinson M, Witham G et al (2005) Exploring the decision-making preferences of people with colorectal cancer. *Health Expect* 8:103–113 doi:10.1111/j.1369-7625.2005.00320.x
- Bruera E, Sweeney C, Calder K, Palmer L, Benisch-Tolley S (2001) Patient preferences versus physician perceptions of treatment decisions in cancer care. *J Clin Oncol* 19:2883–2885
- Bui L, Rempel E, Reeson D, Simunovic M (2006) Lymph node counts, rates of positive lymph nodes, and patient survival for colon cancer surgery in Ontario, Canada: a population-based study. *J Surg Oncol* 93:439–445 doi:10.1002/jso.20499
- Cassileth BR, Zupkis RV, Sutton-Smith K, March V (1980) Information and participation preferences among cancer patients. *Ann Intern Med* 92:832–836
- Cheng JD, Hitt J, Koczwara B, Schulman KA, Burnett CB, Gaskin DJ et al (2000) Impact of quality of life on patient expectations regarding phase I clinical trials. *J Clin Oncol* 18:421–428
- Colorectal Cancer Collaborative Group (2000) Surgery for colorectal cancer in elderly patients: a systematic review. *Lancet* 356:968–974
- Curran D, Giralt J, Harari PM, Ang KK, Cohen RB, Kies MS et al (2007) Quality of life in head and neck cancer patients after treatment with high-dose radiotherapy alone or in combination with cetuximab. *J Clin Oncol* 25:2191–2197 doi:10.1200/JCO.2006.08.8005
- Daugherty CK, Banik DM, Janish L, Ratain MJ (2000) Quantitative analysis of ethical issues in phase I trials: a survey interview of 144 advanced cancer patients. *IRB* 22:6–14 doi:10.2307/3564113
- Degner LF, Kristjanson LJ, Bowman D, Sloan JA, Carriere KC, O'Neil J et al (1997) Information needs and decisional preferences in women with breast cancer. *JAMA* 277:1485–1492 doi:10.1001/jama.277.18.1485
- Demissie K, Oluwole OO, Balasubramanian BA, Osinubi OO, August D, Rhoads GG (2004) Racial differences in the treatment of colorectal cancer: a comparison of surgical and radiation therapy between Whites and Blacks. *Ann Epidemiol* 14:215–221
- Du XL, Fang S, Vernon SW, El-Serag H, Shih YT, Davila J et al (2007) Racial disparities and socioeconomic status in association with survival in a large population-based cohort of elderly patients with colon cancer. *Cancer* 110:660–669 doi:10.1002/cncr.22826
- Elkin EB, Kim SH, Casper ES, Kissane DW, Schrag D (2007) Desire for information and involvement in treatment decisions: elderly cancer patients' preferences and their physicians' perceptions. *J Clin Oncol* 25:5275–5280 doi:10.1200/JCO.2007.11.1922
- Eng C, Maurel J, Scheithauer W, Wong L, Lutz M, Middleton G (2007) Impact on quality of life of adding cetuximab to irinotecan in patients who have failed prior oxaliplatin-based therapy: The EPIC trial. *J Clin Oncol* 25:4003 2007 ASCO Annual Meeting Proc
- Fried TR, Bradley EH (2003) What matters to seriously ill older persons making end-of-life treatment decisions?: a qualitative study. *J Palliat Med* 6:237–244 doi:10.1089/109662103764978489
- Gaskin DJ, Kong J, Meropol NJ, Yabroff KR, Weaver C, Schulman KA (1998) Treatment choices by seriously ill patients: the Health Stock Risk Adjustment model. *Med Decis Mak* 18:84–94 doi:10.1177/0272989X9801800116
- Gaskin DJ, Weinfurt KP, Castel LD, DePuy V, Li Y, Balshem A et al (2004) An exploration of relative health stock in advanced cancer patients. *Med Decis Mak* 24:614–624 doi:10.1177/0272989X04271041
- Gattellari M, Butow PN, Tattersall MH (2001) Sharing decisions in cancer care. *Soc Sci Med* 52:1865–1878 doi:10.1016/S0277-9536(00)00303-8

21. Goldberg RM, Tabah-Fisch I, Bleiberg H, de Gramont A, Tournigand C, Andre T et al (2006) Pooled analysis of safety and efficacy of oxaliplatin plus fluorouracil/leucovorin administered bimonthly in elderly patients with colorectal cancer. *J Clin Oncol* 24:4085–4091 doi:10.1200/JCO.2006.06.9039
22. Gross CP, Guo Z, McAvay GJ, Allore HG, Young M, Tinetti ME (2006) Multimorbidity and survival in older persons with colorectal cancer. *J Am Geriatr Soc* 54:1898–1904 doi:10.1111/j.1532-5415.2006.00973.x
23. Gross CP, McAvay GJ, Guo Z, Tinetti ME (2007) The impact of chronic illnesses on the use and effectiveness of adjuvant chemotherapy for colon cancer. *Cancer* 109:2410–2419 doi:10.1002/cncr.22726
24. Grossman M (1972) On the concept of health capital and the demand for health. *J Pol Econ* 80:168–199
25. Halyard MY, Frost MH, Dueck A (2006) Integrating QOL assessments for clinical and research purposes. *Curr Probl Cancer* 30:319–330 doi:10.1016/j.currprolancer.2006.08.009
26. Harrison LE, Guillem JG, Paty P, Cohen AM (1997) Preoperative carcinoembryonic antigen predicts outcomes in node-negative colon cancer patients: a multivariate analysis of 572 patients. *J Am Coll Surg* 185:55–59
27. Jansen SJ, Otten W, Stiggelbout AM (2004) Review of determinants of patients' preferences for adjuvant therapy in cancer. *J Clin Oncol* 22:3181–3190 doi:10.1200/JCO.2004.06.109
28. Jansen SJ, Stiggelbout AM, Wakker PP, Nooij MA, Noordijk EM, Kievit J (2000) Unstable preferences: a shift in valuation or an effect of the elicitation procedure? *Med Decis Mak* 20:62–71 doi:10.1177/0272989X0002000108
29. Kiebert GM, Stiggelbout AM, Kievit J, Leer JW, van de Velde CJ, de Haes HJ (1994) Choices in oncology: factors that influence patients' treatment preference. *Qual Life Res* 3:175–182 doi:10.1007/BF00435382
30. Kilbridge KL, Weeks JC, Sober AJ, Haluska FG, Slingluff CL, Atkins MB et al (2001) Patient preferences for adjuvant interferon alfa-2b treatment. *J Clin Oncol* 19:812–823
31. Lavori PW, Dawson R (2004) Dynamic treatment regimes: practical design considerations. *Clin Trials* 1:9–20 doi:10.1191/1740774S04cn0020a
32. Lavori PW, Dawson R, Rush AJ (2000) Flexible treatment strategies in chronic disease: clinical and research implications. *Biol Psychiatry* 48:605–614 doi:10.1016/S0006-3223(00)00946-X
33. Law CH, Wright FC, Rapanos T, Alzahrani M, Hanna SS, Khalifa M et al (2003) Impact of lymph node retrieval and pathological ultra-staging on the prognosis of stage II colon cancer. *J Surg Oncol* 84:120–126 doi:10.1002/jso.10309
34. Lee L, Jannapureddy M, Albo D, Awad SS, Farrow B, Bellows CC et al (2007) Outcomes of Veterans Affairs patients older than age 80 after surgical procedures for colon malignancies. *Am J Surg* 194:646–651 doi:10.1016/j.amjsurg.2007.08.003
35. Love N, Bylund C, Meropol NJ, Marshall JL, Curley SA, Ellis LM (2007) How well do we communicate with patients concerning adjuvant systemic therapy? A survey of 150 colorectal cancer survivors. *J Clin Oncol* 25:4020 2007 ASCO Annual Meeting Proc Part I
36. Mackillop WJ, Stewart WE, Ginsburg AD, Stewart SS (1988) Cancer patients' perceptions of their disease and its treatment. *Br J Cancer* 58:355–358
37. Mahoney T, Kuo YH, Topilow A, Davis JM (2000) Stage III colon cancers: why adjuvant chemotherapy is not offered to elderly patients. *Arch Surg* 135:182–185 doi:10.1001/archsurg.135.2.182
38. Maly RC, Umezawa Y, Ratliff CT, Leake B (2006) Racial/ethnic group differences in treatment decision-making and treatment received among older breast carcinoma patients. *Cancer* 106:957–965 doi:10.1002/cncr.21680
39. Meropol NJ, Weinfurt KP, Burnett CB, Balslem A, Benson AB 3rd, Castel L et al (2003) Perceptions of patients and physicians regarding phase I cancer clinical trials: implications for physician-patient communication. *J Clin Oncol* 21:2589–2596 doi:10.1200/JCO.2003.10.072
40. Meyerhardt JA, Catalano PJ, Haller DG, Mayer RJ, Macdonald JS, Benson AB 3rd et al (2003) Impact of diabetes mellitus on outcomes in patients with colon cancer. *J Clin Oncol* 21:433–440 doi:10.1200/JCO.2003.07.125
41. Moertel CG, Fleming TR, Macdonald JS, Haller DG, Laurie JA, Tangen CM et al (1995) Fluorouracil plus levamisole as effective adjuvant therapy after resection of stage III colon carcinoma: a final report. *Ann Intern Med* 122:321–326
42. Murphy DJ, Cluff LE (1990) The SUPPORT study. Introduction. *J Clin Epidemiol* 43(Suppl):V–X
43. Murphy SA, Lynch KG, Oslin D, McKay JR, TenHave T (2007) Developing adaptive treatment strategies in substance abuse research. *Drug Alcohol Depend* 88(Suppl 2):S24–S30 doi:10.1016/j.drugalcdep.2006.09.008
44. National Cancer Institute Surveillance Epidemiology and End Results (SEER) Program (2004) Median age of cancer patients at diagnosis, 2000–2004 by primary cancer site, race and sex. National Cancer Institute
45. O'Connor AM, Boyd NF, Warde P, Stolbach L, Till JE (1987) Eliciting preferences for alternative drug therapies in oncology: influence of treatment outcome description, elicitation technique and treatment experience on preferences. *J Chronic Dis* 40:811–818 doi:10.1016/0021-9681(87)90133-0
46. Ohman U (1982) Prognosis in patients with obstructing colorectal carcinoma. *Am J Surg* 143:742–747 doi:10.1016/0002-9610(82)90050-2
47. Popescu RA, Norman A, Ross PJ, Parikh B, Cunningham D (1999) Adjuvant or palliative chemotherapy for colorectal cancer in patients 70 years or older. *J Clin Oncol* 17:2412–2418
48. Potosky AL, Harlan LC, Kaplan RS, Johnson KA, Lynch CF (2002) Age, sex, and racial differences in the use of standard adjuvant therapy for colorectal cancer. *J Clin Oncol* 20:1192–1202 doi:10.1200/JCO.20.5.1192
49. Prehn AW, Topol B, Stewart S, Glaser SL, O'Connor L, West DW (2002) Differences in treatment patterns for localized breast carcinoma among Asian/Pacific islander women. *Cancer* 95:2268–2275 doi:10.1002/cncr.10965
50. Reuben DB, Naeim A (2004) Perspectives, preferences, care practices, and outcomes in late-stage cancer patients: connecting the dots. *J Clin Oncol* 22:4869–4871 doi:10.1200/JCO.2004.09.960
51. Salkeld G, Solomon M, Short L, Butow PN (2004) A matter of trust—patient's views on decision-making in colorectal cancer. *Health Expect* 7:104–114 doi:10.1111/j.1369-7625.2004.00257.x
52. Schrag D, Cramer LD, Bach PB, Begg CB (2001) Age and adjuvant chemotherapy use after surgery for stage III colon cancer. *J Natl Cancer Inst* 93:850–857 doi:10.1093/jnci/93.11.850
53. Schrag D, Gelfand SE, Bach PB, Guillem J, Minsky BD, Begg CB (2001) Who gets adjuvant treatment for stage II and III rectal cancer? Insight from Surveillance, Epidemiology, and End Results—Medicare. *J Clin Oncol* 19:3712–3718
54. Schwartz CE, Sprangers MA (2002) An introduction to quality of life assessment in oncology: the value of measuring patient-reported outcomes. *Am J Manag Care* 8:S550–S559
55. Simes RJ, Coates AS (2001) Patient preferences for adjuvant chemotherapy of early breast cancer: how much benefit is needed? *J Natl Cancer Inst Monogr* 30:146–152
56. Solomon MJ, Pager CK, Keshava A, Findlay M, Butow P, Salkeld GP et al (2003) What do patients want? Patient preferences and

- surrogate decision making in the treatment of colorectal cancer. *Dis Colon Rectum* 46:1351–1357 doi:[10.1007/s10350-004-6749-0](https://doi.org/10.1007/s10350-004-6749-0)
57. Stiggelbout AM, Jansen SJ, Otten W, Baas-Thijssen MC, van Slooten H, van de Velde CJ (2007) How important is the opinion of significant others to cancer patients' adjuvant chemotherapy decision-making? *Support Care Cancer* 15:319–325 doi:[10.1007/s00520-006-0149-z](https://doi.org/10.1007/s00520-006-0149-z)
58. Townsley C, Pond GR, Peloza B, Kok J, Naidoo K, Dale D et al (2005) Analysis of treatment practices for elderly cancer patients in Ontario, Canada. *J Clin Oncol* 23:3802–3810 doi:[10.1200/JCO.2005.06.742](https://doi.org/10.1200/JCO.2005.06.742)
59. True G, Phipps EJ, Braitman LE, Harralson T, Harris D, Tester W (2005) Treatment preferences and advance care planning at end of life: the role of ethnicity and spiritual coping in cancer patients. *Ann Behav Med* 30:174–179 doi:[10.1207/s15324796abm3002\\_10](https://doi.org/10.1207/s15324796abm3002_10)
60. Watanabe Y, Takahashi M, Kai I (2008) Japanese cancer patient participation in and satisfaction with treatment-related decision-making: a qualitative study. *BMC Public Health* 8:77 doi:[10.1186/1471-2458-8-77](https://doi.org/10.1186/1471-2458-8-77)
61. Weeks JC, Cook EF, O'Day SJ, Peterson LM, Wenger N, Reding D et al (1998) Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA* 279:1709–1714 doi:[10.1001/jama.279.21.1709](https://doi.org/10.1001/jama.279.21.1709)
62. Weinfurt KP, Castel LD, Li Y, Sulmasy DP, Balslem AM, Benson AB 3rd et al (2003) The correlation between patient characteristics and expectations of benefit from phase I clinical trials. *Cancer* 98:166–175 doi:[10.1002/cncr.11483](https://doi.org/10.1002/cncr.11483)
63. Wong JH, Bowles BJ, Bueno R, Shimizu D (2002) Impact of the number of negative nodes on disease-free survival in colorectal cancer patients. *Dis Colon Rectum* 45:1341–1348 doi:[10.1007/s10350-004-6423-6s](https://doi.org/10.1007/s10350-004-6423-6s)
64. Yellen SB, Cella DF (1995) Someone to live for: social well-being, parenthood status, and decision-making in oncology. *J Clin Oncol* 13:1255–1264