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The relationship between cancer patient treatment decision-making roles and quality of life

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Abstract

Background—This study's objective was to explore relationships between patient role preferences during the cancer treatment decision-making process and quality of life (QOL).

Methods—As part of a larger survey conducted by the American Cancer Society, 1-year cancer survivors completed a survey in 2000. This paper is based upon respondents from Minnesota (response rate 37.4%). Standardized measures included the Profile of Mood States (scores converted to have a range, 0-100; 100 is the best mood), the Short Form (SF)-36 (standardized scores), and the Control Preferences Scale. Patients' actual and preferred role preference distributions and concordance between the roles were compared to QOL scores using two-sample t-test methodology.

Results—Survivors (n=594) actual role in cancer care was 33% active, 50% collaborative and 17% passive. Their preferred role was 35% active, 53% collaborative, and 13% passive. 88% of survivors had concordant preferred and actual roles. Survivors with concordant roles had higher SF-36 Physical Component Scores (PCS) (p<0.01), higher vitality (p=0.01), less fatigue (p<0.01), less confusion (p=0.01), less anger (p=0.046) and better overall mood (p=0.01). These results were similar in both the female and the younger (age <60) cohorts. Survivors with active actual roles

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had higher PCS ($p < 0.01$), less tension ($p = 0.04$), and higher vitality ($p = 0.04$) than those being collaborative or passive. No differences existed in QOL scores by preferred role.

Conclusions—Survivors who experienced discordance between their actual role and preferred role reported substantial QOL deficits in both physical and emotional domains. These results are indicative of the need to support patient preferences.

Keywords

quality of life; decision analysis; quality of care; control preferences; cancer survivors

Introduction

The evolution of modern interdisciplinary cancer care and the emergence of personalized medicine have increased the presence and importance of patient-centered communication.¹ Research has demonstrated that two-way communication, shared understanding and trust between patients and health care providers are paramount to the success of treatment.^{2,3,4} Such research has also shown patients desire information regarding medical condition and available treatment options so medical decision making can occur.⁵⁻⁹ In response, cancer care in the United States has made a concerted effort to become more patient-focused and collaborative.^{3,10}

Much has been written about how to provide information and engage patients in making decisions. The optimal approach depends upon the extent of participation (active, collaborative, or passive) the patient wants or needs.^{7,8,11-15} Various studies have explored the degree of involvement patients want. In 1996, Beaver et al, reported the majority (52%) of newly diagnosed breast cancer patients preferred a passive role.¹⁶ This finding was challenged in 2006 as Hack et al. reported only 22% of breast cancer patients preferred a passive role.¹⁷ Late stage disease and tumors of the reproductive system, especially among males, tend to be associated with a more passive approach by patients.^{15,18}

A large, multi-sample study involving cancer patients with a variety of tumors found that roughly 25% of patients prefer to have an active role in treatment decision making, 50% prefer a collaborative role, and 25% prefer to have doctors make decisions for them.¹⁹ Thus it is known that patients' preferred role in medical decision making varies among individuals^{15,20}, but is relatively trait-like, meaning it doesn't change, over time.^{15,18,19} Coulter summarized that “desire for participation has been found to vary according to age, educational status, disease severity and cultural background.”⁵

Past studies with cancer survivor participants have reported associations between Quality of Life (QOL) and satisfaction with control or involvement in health care.^{21,22} Griggs et al (2007) reported treatment satisfaction was associated with an increase in mental health.²³ This report uses population-based data to describe decision making preferences, demographics, and QOL of cancer survivors. Moreover, our aim is to determine if QOL is impacted by patient concordance or discordance in preferred and actual decision making roles.

Methods

Eligibility and Recruitment

The American Cancer Society's (ACS) Study of Cancer Survivors (SCS) is a longitudinal, population-based study of adult cancer survivors designed to examine physical and psychosocial adjustment to cancer, and changes in QOL. The cancer survivors were drawn from 11 state cancer registries. The study had the approval of the Institutional Review Board (IRB) of Emory University. Additional IRB approvals were obtained in each state. Details of the complete study design and analysis have been previously reported.²⁴ This paper reports on results of Minnesota survivors using the SCS survey as administered at 1 year post-diagnosis, conducted by the ACS, the Minnesota Cancer Surveillance System (Minnesota's cancer registry), and the Mayo Clinic (IRB 0-2462-01).

Newly diagnosed cancer patients were selected from the state cancer registry and screened for eligibility. To be eligible to participate, patients had to be at least 18 years of age, diagnosed with one of the ten most common cancers (prostate, female breast, lung, colorectal, bladder, Non-Hodgkin's lymphoma, skin melanoma, kidney, ovarian and uterine) and have stage I-IV at the time of diagnosis. Patients were ineligible if they were identified as being mentally incompetent by their physicians, or were institutionalized or incarcerated at the time of recruitment. Physicians identified in the state cancer registry were notified that their patient had been sampled for this study and given an opportunity to update patient eligibility. Subsequently, survivors were consented and surveyed via mail and telephone. The overall response rate in Minnesota, including physician notification and survivor recruitment, was 37.4%. The methodological implications of this low response rate were discussed in detail by Smith et al (2007).²⁴

Measures

Patient decision making preferences were measured by the Control Preference Scale (CPS) (Figure 1).²⁵ The two-item tool allows the patient to record their actual (item 1) and preferred (item 2) roles in decision making. The goal of the development of this tool was to allow clinicians to assess patient role preferences and experiences in order to facilitate communication.

Patient health related QOL was measured by the 36 item SF-36 Health Survey which is a validated self-reported tool composed of questions regarding health status, feelings and ability to do usual activities as recollected during the last 4 weeks.^{26,27} The SF-36 measure is comprised of 2 summary scales. The Physical Component Scale (PCS) is composed of physical functioning, physical role functioning, bodily pain and general health indexes. The Mental Component Scale (MCS) is composed of vitality, social functioning, emotional role functioning and mental health indexes. The summary scales and indexes are standardized and age-adjusted.

Patient mood was measured by the Profile of Mood States (POMS).²⁸ The POMS consists of 37 items, each rated on a scale from 0-5 with 0 meaning 'no' and 5 meaning 'always'. Each item asks the patient if he or she has experienced a particular feeling in last week. Sample items are "unhappy", "lively", "worn-out", "tense", "angry", and "unable to

concentrate”. The POMS produces an overall score and a score for each of 6 subscales: anger-hostility (A/H), confusion-bewilderment (C/B), depression-dejection (D/D), fatigue-inertia (F/I), tension-anxiety (T/A), and vigor-activity (V/A).

Statistical Considerations

All assessments were scored using the appropriate algorithms. In order to improve interpretability and comparability, the POMS total and subscale scores were converted to a 0-100 point scale, where 100 represented the best possible mood or QOL; so, a higher number means better mood or QOL. Both PCS and MCS are norm-based with a mean of 50 and standard deviation of 10. Higher scores are indicative of better health status.²⁷ Responses to the CPS were used to categorize patients actual and preferred roles as active, collaborative, or passive.¹⁵ Further, actual and preferred CPS responses were compared. If actual role and preferred role were the same, the patient's role agreement was categorized as being concordant. If they were not the same, the patient's role agreement was categorized as being discordant.

Role preference distributions were compared to demographic categories and QOL scores using Fisher's exact, two-sample t-test and Kruskal-Wallis methodology, as appropriate. General linear modeling techniques were employed to determine any relationships between QOL scores of PCS, MCS and POMS mood as dependent variables with baseline characteristics and CPS scores as independent variables.

With 594 observations, with approximately 7.4 times as many subjects in the Concordance group than in the Discordance group, a two-sample t-test (with a 0.05 two-tailed test of significance) has 80% power to detect a mean difference that equals 0.36 times the pooled standard deviation of the two groups), suggesting a standardized effect size of 0.36.²⁹

Results

Patient Population

There were 594 eligible patients. They completed the CPS and at least one of the POMS or SF-36 questionnaires approximately 1 year after diagnosis. Baseline characteristics indicate the survivors were predominantly over the age of 60 (54%), were female (54%), had breast (23%) or prostate (21%) cancers, and had treatment of chemotherapy (32%), radiation therapy (30%) or surgery-resection (66%) (Table 1). The majority (59%) of patients had at least one comorbidity. Asthma (9%), depression (8%), diabetes (7%), heart condition (8%), high blood pressure (31%), or 'other' (12%) were most frequently reported.

CPS Responses

CPS results indicate 33% of survivors actually played an active role in treatment decision-making, 50% played a collaborative role, and 17% played a passive role (Table 2). The role preferred had approximately the same distribution. The patient population had a distribution of role agreement of 523 (88%) concordant and 71 (12%) discordant. The Kappa statistic indicates in this sample we would conclude that there is 80% more agreement than we would expect by chance alone. Of the patients reporting discordance, 52 (73%) played a role

that was more active than preferred and 19 (27%) played a role that was less active than preferred. There were no demographic differences between concordant patients and discordant patients.

CPS Results and QOL Scores

Kruskall-Wallis analysis showed patients reporting an actual active role had higher SF-36 PCS scores (mean of 46.5 vs. 43.7 for collaborative and 42.5 for passive, $p < 0.01$), higher SF-36 Physical Function index (mean of 51.3 vs. 49.5 for collaborative and 47.9 for passive, $p = 0.04$), higher POMS tension/anxiety scores (mean of 82.8 vs. 81.4 for collaborative and 76.3 for passive, $p = 0.04$) and higher POMS vitality scores (mean of 50.8 vs. 48.6 for collaborative and 44.4 for passive, $p = 0.04$) (Figures 2,3). Survivors' actual role was not related to SF-36 MCS scores, POMS total score, or other POMS subscale scores. Survivors preferred role was not related to any mean QOL scores.

The primary aim of this study was to determine whether patient concordance or discordance of preferred and actual roles had an impact on QOL. Survivors with concordant roles reported better QOL scores than those with discordant roles. Specifically, they had higher mean SF-36 PCS (45.0 vs. 40.5, $p < 0.001$) score and better mean POMS mood score (77.4 vs. 73.1, $p = 0.01$) (Table 3). SF-36 index analyses indicated better scores in concordant patients for physical functioning (50.2 vs. 47.5, $p = 0.02$), bodily pain (51.0 vs. 47.9, $p = 0.01$), general health (50.5 vs. 45.6, $p < 0.01$) and vitality (49.1 vs. 45.4, $p = 0.01$). POMS subscales indicate concordant patients indicated less anger (88.0 vs. 84.9, $p = 0.046$), higher vitality (49.5 vs. 42.3, $p = 0.01$), less fatigue (70.2 vs. 60.0, $p < 0.01$), less confusion (84.1 vs. 79.5, $p = 0.01$) and better overall mood (POMS total) In a subset analysis, younger concordant patients (age less than 60) and female concordant patients had similar results compared to their discordant counterparts. Older discordant patients only had significantly lower PCS (38.9 vs. 43.0, $p = 0.03$) and vitality (41.6 vs. 51.3, $p = 0.02$) scores as compared to older concordant patients and male discordant patients only had worse fatigue as compared to male concordant patients (62.1 vs. 72.4, $p = 0.02$). There were no differences in any QOL scores within the discordant group when comparing those who played a role that was more active than preferred ($n = 52$) vs. those who played a role that was less active than preferred ($n = 19$).

Generalized Linear Modeling techniques were employed to determine if baseline characteristics (age, gender, race, cancer treatment) and CPS defined concordance were predictive of PCS, MCS and mood scores. Results indicate that age is statistically significant in each model and concordance is significant in the PCS and POMS models. The amount of variance accounted for by age and concordance was small ($< 5\%$) with R^2 values less than 0.08, indicating that QOL scores were highly individualistic relative to the demographics that were recorded. Hence, little variation in the set of predictors explained the variation in the outcomes.

Discussion

This study of cancer survivors who had completed assessments within 1 year post-diagnosis confirmed previously posited relationships between the decision-making role and QOL

domains. Discordance between actual and preferred roles resulted in poorer physical health and poorer mood (anger, confusion, fatigue and vigor) but did not result in worse mental well-being. Similar results were found within the younger patient and female subsets. Survivors whose actual role was active, had less tension and more vigor. Poorer QOL for discordant survivors was not dependent upon the direction of the discordance. Previous research has shown that that treatment satisfaction and QOL are related.^{4,30,31} Our findings go beyond this to support the hypothesis that role satisfaction, not just treatment satisfaction, impacts patient QOL.

Dow et al and both Hodgkinson et al. studies (2007)^{7,13,14} have indicated that making decisions regarding health care was an important need of patients. Patients wished to have some control,^{7,13} and most frequent unmet goals were in the domain of existential survivorship, as indicated on the Cancer Survivors Unmet Needs measure, which included items such as ‘cope with changes to my beliefs’; and ‘make decisions about my life in context of uncertainty.’¹³ Breast cancer survivors report that being informed regarding medical decisions is one of the most important pieces of advice to give newly diagnosed patients, thus confirming patient preference to play an active role in decision making.¹¹ A recent systematic review found an increasing trend in patient preferences for shared decision making; in 50% of studies published prior to 2000 the majority of patients preferred to share decisions, this increased to 71% of studies published in 2000 or later.³² These studies did not, however, have any comparisons between the decision making and QOL.

Yet satisfaction with treatment and care patterns has been associated with QOL. In particular, Griggs (2007) reported a relationship between satisfaction of information and vitality, mental health and distress.²³ Satisfaction likely has several components to it including patient-physician interaction, access to care, quality of care and outcomes. One important component of satisfaction in patient-physician interaction during cancer treatment is the degree to which a patient plays his or her preferred role in cancer treatment decision making. Our study found better physical and emotional QOL in patients who played an active role and in those with concordance between preferred and actual role played. Similar to Griggs et al, our study found concordance of roles was associated with higher vitality (POMS V/A) and better overall mood (POMS total score). Unlike Griggs (2007) results, mental health was not associated with an actual or preferred decisional role in our study.

Regardless of the role preferred, survivors in our study who experienced their preferred level of input into the decision making process reported better QOL and associated outcomes. Survivors with concordant actual and preferred roles may be more adherent to treatment protocols, therefore, resulting in higher QOL scores in some areas. Or, it could be that concordant roles led to improved knowledge, self-efficacy, and/or self-management in these patients, thus improving QOL.

A recent meta-analysis found that information needs were greatest among those who preferred an active role in treatment decisions.³³ Information satisfaction has been related to global QOL, physical well-being, social well-being, emotional well-being, and functional well-being in descriptive studies.³⁴ Arora et al. (2002) found that access to information was associated with better well-being and higher perceptions of health competence.³⁵ Patients

playing their preferred role may have more appropriate access to information, which may lead to better QOL. Other speculations include those playing a preferred role might find the experience less distressing. People who prefer active or collaborative roles and do not attain them might become frustrated. Those who prefer a more passive role may become overwhelmed when physicians ask them to engage in decision making.

This study recorded control preferences at 1 year post treatment. A reasonable question is to ask if the findings would have been different had the CPS had been recorded at various time points. We have seen CPS scores change very little in the short term (within 6 months). However, there are very limited data on the longitudinal nature of control preferences. One study (Hack (2005)) reports a 48% concordance in baseline role assumed vs role preferred 3 years later. The CPS would seem to be more trait-like than state-like.

When considering the clinical implications of our results, we considered minimally important differences. Although there are many methods for establishing and many factors influencing minimally important differences, previous work has often found differences of a half standard deviation in HRQOL measures to be clinically important³⁶; variability in thresholds is underscored by a study suggesting that differences as low as 0.1 standard deviation could be important in certain situations³⁷. In our study, statistically significant differences between concordant and discordant patients ranged in size from roughly one half standard deviation for SF-36 PCS to a little less than a third of a standard deviation for the POMS Total Mood score. This amounts to a 5 point difference in the SF-36 PCS (which reports a minimum clinically important difference in the range typically of 3-5 points) relative to a population norm of 50 and a 4 point difference in the POMS relative to a population norm of 75. Results such as these suggest that clinicians should encourage patients who are discordant to pursue a preferred role in order to improve QOL.

Current endeavors in augmenting patient-centered care, which involves systematic evidence based structures aimed at integrating the patient's perspective more formally into the decision making process, involves the use of patient-reported outcomes (PROs) in a paradigm of treatment and referral (Figure 4). Our results support the use of this paradigm. The model in Figure 4 indicates an integrated flow of information and decision making processes between the patient and the health care team which will promote improved care, QOL, and patient outcomes. PROs are assessed regularly at each patient clinical appointment and results are communicated to the clinical team. Within our context, patient-centric care considers that patients playing a preferred role may receive a wide array of benefits. The entire health care system is moving towards patient-centric care which means our results are particularly timely. This is relevant to the Patient-Centered Outcomes Research Institute (PCORI) and its recent mandate to generate standardized methods and applications to improve patient-centered care.³⁸ Our data suggest that the benefits hypothesized by PCORI's focus on patient-centered care are empirically demonstrable.

There were methodological limitations of the ACS survey documented by Smith (2007) that mandate caution in broad interpretation of our findings. In particular, the relatively low response rate puts into question the generalizability of our results to the general adult cancer population. Further the results were recorded at 1 year post diagnosis which prevents a

longitudinal profile from being constructed and examined for differences in our findings over time. Finally our data are derived strictly from a data set comprised of patients from the upper mid-west.

Conclusions

Patients having discordance between their preferred and actual roles in cancer care reported substantial QOL deficits in both physical and emotional domains. Improved patient satisfaction with care and improved QOL may be achieved by meeting patient expectations with respect to the amount of input they have in making treatment decisions.

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1. Circle the letter next to the phrase below that best describes the role you have actually been playing in dealing with your cancer diagnosis.

<i>The Control Preferences Scale</i>	
Active Role	Passive Role
<p>A. I prefer to make the decision about which treatment I will receive.</p> <p>B. I prefer to make the final decision about my treatment after seriously considering my doctor's opinion.</p>	<p>E. I prefer to leave all decisions regarding my treatment to my doctor.</p> <p>D. I prefer that my doctor makes the final decision about which treatment will be used, but seriously consider my options.</p>
	
<p>Collaborative Role</p> <p>C. I prefer that my doctor and I share responsibility for deciding which treatment is best for me.</p>	

2. Circle the letter next to the phrase below that best describes the role you would **have preferred**.


<i>The Control Preferences Scale</i>	
Active Role	Passive Role
<p>A. I prefer to make the decision about which treatment I will receive.</p> <p>B. I prefer to make the final decision about my treatment after seriously considering my doctor's opinion.</p>	<p>E. I prefer to leave all decisions regarding my treatment to my doctor.</p> <p>D. I prefer that my doctor makes the final decision about which treatment will be used, but seriously consider my options.</p>
	
<p>Collaborative Role</p> <p>C. I prefer that my doctor and I share responsibility for deciding which treatment is best for me.</p>	

Figure 1.
Control Preferences Scale.

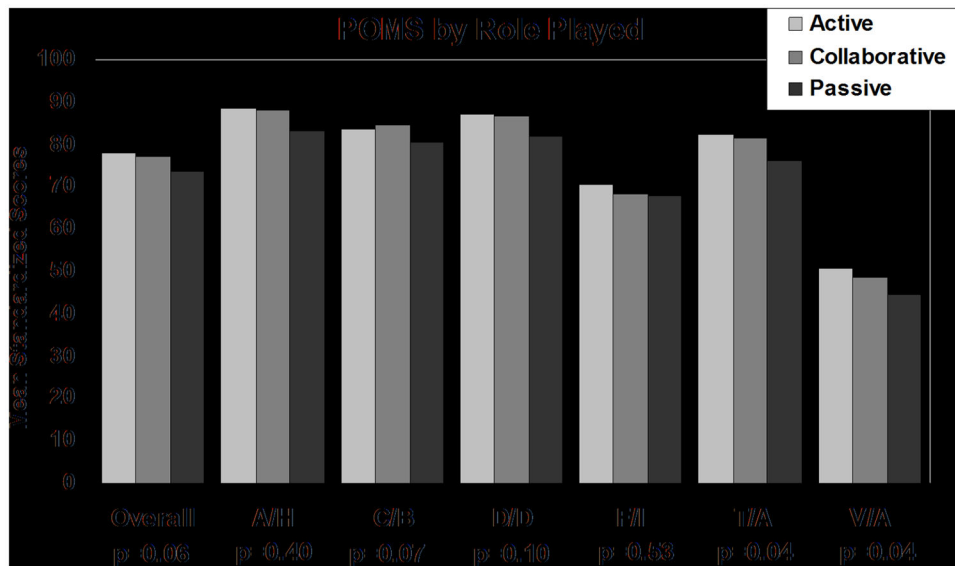


Figure 2. Profile of Mood States Scores by Role Played

Statistically significant differences occurred for Tension/Anxiety and Vigor/Activity. P-values are based on the Kruskal-Wallis nonparametric test.

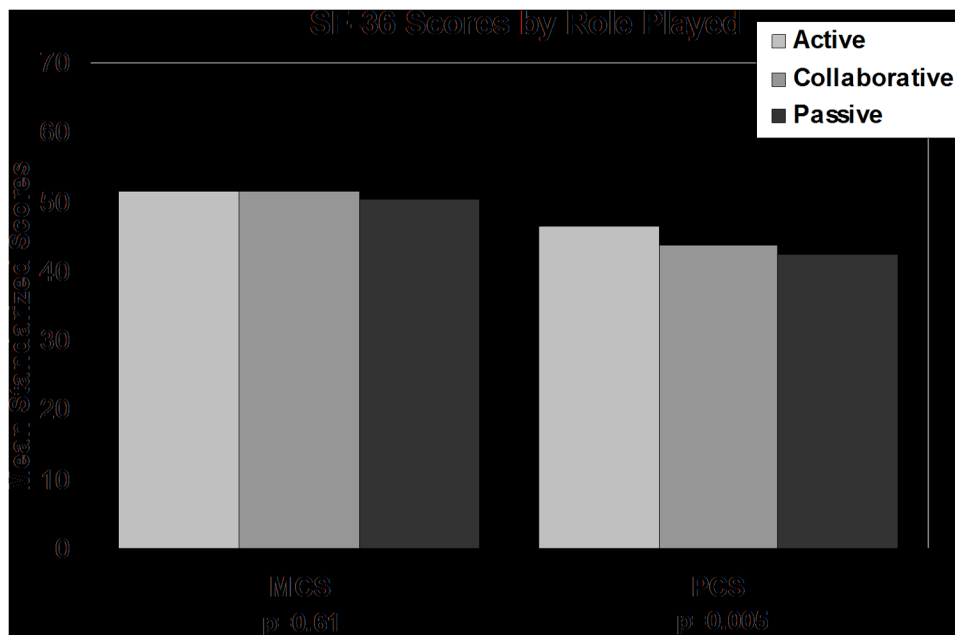


Figure 3. SF-36 Scores by Role Played

The Physical Component score was statistically significantly different between roles played. P-values are based on the Kruskal-Wallis nonparametric test.

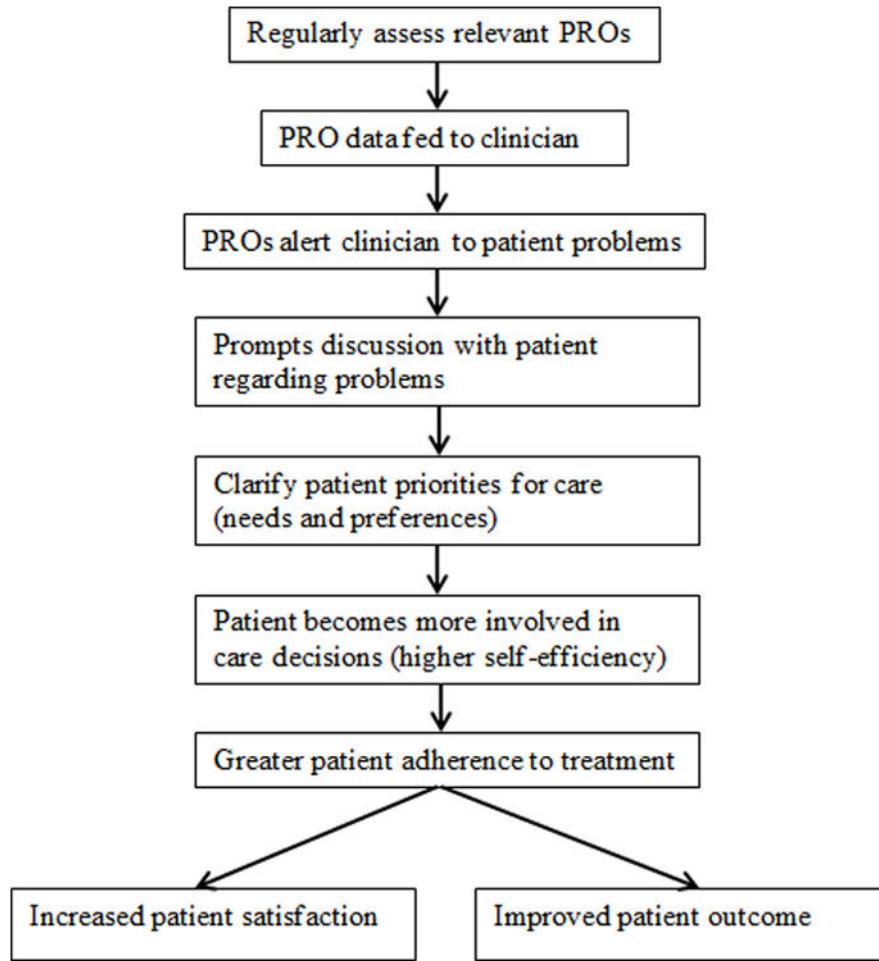


Figure 4. Use of Patient Reported Outcomes to Enhance Patient-Centered Care

Table 1
Patient Baseline Demographics (N=594)

	Total		Total
Age Group		Gender	
Under 60	273 (46.0%)	Female	330 (55.6%)
60 & Over	321 (54.0%)	Male	264 (44.4%)
Cancer Type		Cancer Treatment	
Bladder	19 (3.2%)	Surgery - Resection	392 (66.0%)
Breast	134 (22.6%)	Chemotherapy	188 (31.6%)
Colorectal	90 (15.2%)	Radiation	179 (30.1%)
Kidney	27 (4.5%)	Bone Marrow Transplant	4 (0.7%)
Lung	78 (13.1%)	Hormone Therapy	73 (12.3%)
Non-Hodgkins	31 (5.2%)	Immunotherapy	14 (2.4%)
Ovarian	30 (5.1%)		
Prostate	126 (21.2%)	Race	
Skin/Melanoma	23 (3.9%)	White	578 (97.5%)
Uterine	36 (6.1%)	Black	3 (0.5%)
		Other	12 (0.8%)

Table 2
Patient Control Preferences Scale Distribution (N=594)

Control Preferences Scale Summary	
Actual Role Played	
Active	196 (33%)
Collaborative	299 (50%)
Passive	99 (17%)
Role Preferred	
Active	208 (35%)
Collaborative	312 (52.5%)
Passive	74 (12.5%)
Role Agreement	
Discordance	71 (12%)
Concordance	523 (88%)
Discordant Category	
Role played was more active than preferred	52 (73%)
Role played was less active than preferred	19 (27%)

Table 3
Concordance/Discordance in Preferred and Actual Control Preferences Scale Roles with Quality of Life Scores (Mean (SD))

	Concordance (N=523)	Ddiscordance (N=71)	Total (N=594)	p value
SF-36				
Physical Component Score	45.0 (11.0)	40.5 (10.7)	44.5 (11.1)	0.001
Physical Functioning Index	50.2 (9.6)	47.5 (10.1)	49.8 (9.7)	0.02
Physical Role Functioning	47.9 (10.8)	45.2 (11.2)	47.5 (10.9)	0.05
Bodily Pain	51.0 (9.3)	47.9 (9.1)	50.6 (9.3)	0.01
General Health	50.5 (10.4)	45.6 (10.8)	49.9 (10.6)	<0.01
Mental Component Score	51.4 (10.0)	51.1 (9.9)	51.4 (10.0)	0.65
Vitality	49.1 (10.0)	45.4 (10.8)	48.6 (10.1)	0.01
Social Functioning	50.6 (9.2)	48.1 (10.3)	50.3 (9.4)	0.07
Emotional Role Functioning	49.0 (10.7)	49.2 (10.0)	49.0 (10.6)	0.80
Mental Health	51.1 (8.9)	50.5 (9.4)	51.0 (9.0)	0.74
POMS				
Total POMS	77.4 (14.9)	73.1 (15.0)	76.9 (15.0)	0.01
Anger/Hostility Subscale	88.0 (14.8)	84.9 (15.9)	87.6 (15.0)	0.046
Confusion/Bewilderment Subscale	84.1 (14.7)	79.5 (16.6)	83.6 (15.0)	0.01
Depression/Dejection Subscale	86.5 (17.1)	85.3 (17.0)	86.4 (17.1)	0.28
Fatigue/Inertia Subscale	70.2 (23.1)	60.0 (26.6)	69.0 (23.8)	0.002
Tension/Anxiety Subscale	81.3 (17.8)	79.3 (19.1)	81.0 (18.0)	0.47
Vigor/Activity Subscale	49.5 (22.2)	42.3 (23.8)	48.7 (22.5)	0.01

SD= Standard Deviation