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Factors Associated with Oncology Patients' Involvement
in Shared Decision-Making During Chemotherapy

By

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ABSTRACT

Factors Associated with Patients' Involvement in Shared Decision-Making During Chemotherapy

by

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Master of Science in Health and Medical Sciences

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Oncology patients are increasingly encouraged to play an active role in treatment decision making. Taking a more active role in decision-making has been linked to better outcomes, including quality of life, patient satisfaction, and physical and emotional health. While previous studies examined relationships between demographic factors and decision-making roles, less is known about whether psychological, psychosocial adjustment, and symptom-related variables are associated with decision-making roles among patients undergoing cancer treatment.

As part of a study of symptom clusters, patients ($n = 862$) undergoing chemotherapy for breast, gastrointestinal, gynecological, or lung cancer were assessed in terms of demographic, clinical, symptom-related, and psychological and psychosocial adjustment variables. Treatment decision-making roles (preferred role, as well as the role the patient actually played) were assessed with the Control Preferences Scale; decision-making roles (preferred and actual) were classified as passive, collaborative, or active. Predictors of decision-making roles were analyzed using multivariate ordinal logistic regression.

Over half of patients (56.3%) reported that they preferred, and actually played, a collaborative role. In addition to age, education, and income, decision-making role was significantly associated with several coping and personality variables, and with several clinical features, including sleep disturbance, fatigue, and number of comorbid conditions. In a regression model, age, income, fatalism, humor-based coping, and fatigue made unique significant contributions toward predicting decision-making role.

Correlations between psychosocial variables and decision-making role reveal a picture of the intrapersonal resources required to participate actively in decision making. People who were more resilient, used more adaptive coping strategies, and a more open personality tended to prefer a more active role. These factors indicate that coping variables, coupled with patients' ability to understand and incorporate new information, may influence how patients participate in shared decision making.

CONTENTS

- I. Abstract
- II. Acknowledgements
- III. Background
 - a. Shared decision making (SDM)
 - b. Decision making roles
 - c. Participation in SDM as coping strategy
 - d. Factors associated with patient's decision-making role
 - e. Justification & conclusion
 - f. Measures used in my study
- IV. Original research
- V. References
- VI. Appendices
 - a. Demographic and Clinical Characteristics (Table 1)
 - b. Physical and Psychological Symptoms (Table 2)
 - c. Psychosocial Adjustment Characteristics (Table 3)

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BACKGROUND

I. Shared decision making (SDM)

Historical antecedents & ethical justifications

Over the past four decades, there has been a shift in the doctor-patient relationship away from the paternalistic dynamic of physician-driven care toward a relationship in which acknowledgement of and respect for the patient's individual autonomy has become a guiding principle.¹ As late as the 1980s, the most prevalent approach to decision-making was that of a paternalistic physician assuming the dominant role and the patient deferring to a constructed professional authority.² In fact, in 1961, as many as 90% of physicians surveyed would withhold a diagnosis of cancer from their patient.³

More recently, there has been an increasing emphasis on individual autonomy and decision-making, which is at the center of the movement toward patient-centered care and shared decision-making (SDM). Although some have argued that enabling patients to express their autonomy in health care decisions is sufficiently justified on humane and ethical grounds, there have also been data that suggest that more engaged patients are more informed and more likely to fully deliberate about the risks and benefits of the differential treatment options.⁴ Furthermore, there is also evidence that more informed and involved patients have better psychosocial and physical outcomes.⁵ Making decisions in cancer treatment may be especially challenging because of the complex nature of the clinical encounter in which evaluative testing and cancer disease management decisions are increasingly complicated.⁴

While encouraging patients to participate in decision-making has been justified by citing better outcomes among those patients who participate more actively, caution must be exercised in interpreting the results of these studies because not all patients want to take on an active role in decision-making. Nonetheless, several studies have linked an active role in decision-making with better outcomes, including better health outcomes and more satisfaction.⁶⁻⁹ For example, Kaplan et al. found that "good health," whether subjective or measured as functional status, was related to the patient's conversational behavior during physician office visits. Patients who were more directive (asked more questions, attempted to direct the flow of conversation) were less impacted by their chronic condition and more frequently had "good health." Conversely, more direction by the physician (asking questions, giving directions, interrupting) was related with poorer reported health.¹⁰ Though it is possible that healthier patients were more able to engage actively and to exert control than those patients with poorer health status, justifications for encouraging patients to take on an active role in decision-making have been based in outcomes such as this. To this end, studies have shown conflicting associations between health status and role preference, while others have shown no association.¹¹⁻¹⁴ While some patients prefer to take on an active role in making treatment-related decisions, other patients prefer to delegate decision-making to their physician. Thus, patients can be active – becoming more outwardly engaged in the decision-making process – or passive – requesting that or allowing for their physician to make treatment-related decisions on their behalf.

Finally, the changing health care environment, which has grown both more complex and more patient-centered over the past three decades, may contribute to changes in the way that patients may be relating to participation in shared decision-making (SDM). For example, a recent review found that studies conducted before the year 2000 were more likely to find that

patients preferred a more passive role in decision-making compared to studies conducted after that year.¹⁵ This indicates that patients may prefer to be more involved in decision-making as time goes on.

Defining shared decision-making (SDM)

Shared decision-making (SDM), one model of clinical decision-making, differs from other models such as the paternalistic model and the informed model.² With roots in the ethical principle of respect for autonomy, as well as data that indicate patient participation in decision making may be associated with better psychological and physiological outcomes, the idea of shared decision making (SDM) has become an important aspect of the patient-physician relationship and communication process.^{6,16-20} In a 2001 report, the Institute of Medicine advocated for an overhaul of the way in which medical care is organized and delivered, naming SDM as a key mechanism of patient-centered care.²¹ Later, with the passage of the Affordable Care Act (specifically, section 3506), SDM gained even greater interest and became politically institutionalized with the creation of “grants or contracts that develop, test, and disseminate education tools that help patients and caregivers understand and communicate their preferences and values regarding treatment options.”²² Indeed the use of shared decision making has become one important aspect of delivering quality health care, exemplifying the importance – both ethically and clinically – of involving patients in decision-making about medical care.²¹

While shared decision-making (SDM) has become an important and advocated-for feature of patient care, different types and levels of patient and physician participation have been used to define this approach. Shared decision making, as defined by Elwyn et al. is an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences.²³ In a different and widely cited definition, Charles et al. characterize SDM as incorporating simultaneous interaction by both the patient and physician in all stages of the decision-making process with two-way information exchange in which the physician brings knowledge of treatment options and the associated risks and benefits, and the patient brings personal information about his or her illness, lifestyle and values.²⁴ On the one hand, Elwyn et al.’s definition leaves most of the actual task of making a decision to the patient, who weighs the evidence for and against available options against their own preferences, values, and beliefs. Charles et al.’s definition, on the other hand, describes more a process of both the patient and physician working together to share their different knowledge bases and to reach a decision via collaboration. Indeed, when interviewed by Shay et al in 2014, most patients in a general medicine clinic described SDM as a process that ends in a decision that is mutually agreed upon by the patient and physician, emphasizing that a trusting relationship must be built over time.²⁵

Funds of knowledge – personal & professional expertise in SDM

The key objectives of shared decision-making (SDM) are achieved when (1) patients are fully informed of the treatment options and the trade-offs between risks and benefits, and (2) patient values and preferences are incorporated into treatment decisions.⁴ In Charles et al.’s definition, patients are seen as bringing a certain “personal expertise” that incorporates a set of

beliefs and values that can influence preference for treatment. Components of this “personal expertise” are personal values and preferences about treatment options, personal beliefs about various health states and attitudes towards them, past experiences, and the current psychological state – all of which can influence the context of decision making and the ultimate treatment choice.²⁶ Physicians, on the other hand, are seen as contributing a “professional expertise” stemming from scientific and clinical knowledge of a particular disease state and the treatment options available to address that state, usually involving making a treatment recommendation.²

These two aspects of expertise must be brought together in order to generate a shared decision. As modeled by Charles et al., the four necessary characteristics of a shared decision are:

- Patient and physician are involved in the treatment decision-making process,
- Both the physician and the patient share information with each other,
- Both the physician and the patient take steps to participate in the decision-making process by expressing treatment preferences, and
- A treatment decision is made and both the physician and patient agree on the treatment to implement

In this model, the patient and physician reach a mutual agreement about the best treatment to implement during a dynamic process of back and forth discussion. The required two-way discussion between patient and physician is necessitated by the differing expertise brought to the table by each party. According to Charles et al., for a patient to be involved in SDM means that the patient is willing to engage in the decision-making process – essentially, that the patient is willing to take responsibility for disclosing preferences, asking questions, weighing and evaluating treatment alternatives and formulating a treatment preference.²⁷ The stages of SDM include information exchange, deliberation about treatment options, and agreement about the treatment to implement. These stages may occur simultaneously or in an iterative process.²⁸ Interestingly, however, when interviewed about their concept of shared decision-making, Shay et al. found that for patients to label a decision as “shared” that agreement between patient and physician on a particular treatment may be more important than the actual decision-making process.²⁵

In order to involve the patient’s and physician’s particular expertise in a meaningful way, decisions that are to be shared must involve trade-offs between two components: a knowledge component and a values component. To fulfill the knowledge component, the patient must have reasonable knowledge of the risks and benefits of each course of action, which is usually obtained from a health care professional. This knowledge component must then be integrated with the preference component, which exists within the patient.²⁹ This dichotomy between the mutually reliant preference and knowledge components makes figuring out how to integrate the two a central requirement of shared decision-making (SDM). Since transferring information from the physician to the patient is easier than transferring each patient’s values to the physician, Gafni et al. conclude that the most practical model of SDM is that physicians should share their technical expertise with patients and that patients should, in turn, assimilate that information with their values to reach a treatment decision.²⁹ This model, which aligns most closely with the concept of SDM put forth by Elwyn et al., emphasizes the patients’ role in the act of decision-making rather than in the process of collaborating with their physicians.

Even if patients are able to incorporate information relating to statistical odds of success for various therapeutic alternatives, they may tend to make decisions based on what they believe is important for themselves, their families, and their lives rather than the assimilated knowledge-

based information.²⁶ Though exchange between patient and physician is essential to shared decision-making (SDM), research into the operational meaning of SDM suggests that doctor and patients may have differing definitions.³⁰ For example, in qualitative work with patients in a general medicine clinic, Shay et al. found that, for patients, shared decision-making embodied a process that ends in a decision that is mutually agreed upon by the patient and physician.²⁵ In contrast, in a different qualitative study involving interviews with oncologists and surgeons, Charles et al. found that several physicians perceived shared decision making as an interactive process, but one in which the physician still had the final word about the treatment to implement in cases where the patient and physician initially disagreed.³¹ Further, in their review investigating differences between patient and physician perceptions of SDM for a variety of cancer-related and non-cancer-related health conditions, Muhlbacher et al. found that patients tended to place much higher values on long-term side effects, as well as on quality of life when compared to physicians.³² From this work we can see that patients and physicians may not always value various aspects of decision-making in the same ways, which may, in turn, influence the way that they participate and view shared decision-making.

Information sharing

To facilitate the integration of personal and professional expertise, information must be shared bi-directionally – that is, the physician must communicate the appropriate medical information so that the patient can make an informed choice and the patient must communicate his or her own preferences, questions, expectations, and decisions. It is not surprising then that much of the work on patient's decision-making roles has focused on aspects of information sharing. Studies have consistently shown that most patients want to be informed and that very few wish to have no information at all.³³⁻³⁵ However wanting information and wanting to participate in decision-making are not equivalent. In this vein, a review of studies demonstrated that a higher proportion of patients wanted information than wanted to participate in decision-making.³⁶ Furthermore, physician's perceptions of the amount of information desired by their patients and preferred level of involvement in decision-making may not always accurately reflect the preferences of their patients. In 1984, Strull et al. found that clinicians generally underestimated the amount of information and discussion about therapy that patients desired and that they simultaneously tended to overestimate patients' preferences for involvement in shared decision-making (SDM).³³ Later work (Guadignoli et al. 1998, Wittmann et al. 2011) has also shown that physicians tend to underestimate the amount of information that patients want, the extent to which patients want to be involved with decision-making, and do not have a good sense of what influences patients' preference for treatment.^{17,37} Therefore, in light of potential discrepancies between patient and physician perceptions of shared decision-making, Janz et al. suggest that physicians may need to ask directly about role preferences instead of trying to discern them from the opinions offered or questions asked.³⁸

Even though different information may be of varying importance to patients and their physicians, one thing patients and physicians do seem to agree on is that information sharing alone is not sufficient for participation in SDM. When surveying patients and their physicians, Pieterse et al. found that a minority of patients explained participation in decision-making exclusively in terms of being informed and that none of the physicians interviewed agreed that information sharing is sufficient for involvement.³⁹ Though information exchange, in and of

itself, is insufficient to qualify as SDM, we do know that patients tend to be more actively involved when they have enough information about their treatment options.¹⁷ Indeed, although information is not the only requirement for SDM, inadequate information can preclude involvement by patients because uninformed patients feel they are more reliant upon medical staff to make decisions for them.¹¹ Therefore, information sharing is necessary but not sufficient in the process of shared decision-making and SDM encompasses a larger construct of collaboration and sharing preferences and opinions between patient and physician.

This notwithstanding, however, it is important to recognize that information sharing itself is not a neutral process and by the manner in which information is shared may impact a patient's decision and preferred level of involvement in making decisions.⁴⁰ In fact, although intended to facilitate a patient's active involvement in SDM, information sharing can become a means of controlling a patient's decision. For example, there is evidence that some physicians may prolong SDM discussions with patients who initially disagree with their treatment recommendation until the patient agrees with the physician's recommendation.⁴¹ It is therefore important to distinguish information sharing from shared decision-making because, although mutually reliant, focusing on information sharing as a proxy for understanding SDM obscures the more complex processes required for decision-making. Decision-making is a multifaceted task that necessarily involves not only factual understanding of one's options, but also a personal sense of what it means to participate and the ability to integrate information with one's personal values and beliefs.

Information sharing is a prerequisite for SDM because understanding is required for informed choice, however sharing information may not necessarily represent the same concept as sharing a decision. In some cases, a physician may perceive certain information as central to the ability of a patient to make a decision, but patients may not always see it the same way. While physicians viewed knowledge of medical information pertaining to disease and treatment as crucial for patient autonomy, for some patients, information and knowledge may play a different role. Patients may view information as providing psychological reassurance or as a mechanism of trust building between themselves and their physician. In their study of patients with prostate cancer, Orom et al. observed that the value of information for the patient may lie not only in its potential use as an aid to decision-making, but more importantly, in the psychological reassurance or reduced uncertainty facilitated by knowing more.⁴² Furthermore, some clinicians perceive that their patients' cognitive limitations were a greater barrier to participation in decision-making than was perceived by patients of those physicians.³⁹ In interviews with a group of people with cancer who had refused at least one treatment, Van Kleffens et al. found that information and knowledge was not central to the process of deciding to refuse a recommended treatment.⁴³ Instead of information, patients related that the experiences of close friends or family members with cancer, as well as the influence of relatives or friends were more important factors in their decision to refuse a treatment. This suggests that knowledge alone is insufficient and that patients also need their beliefs and emotions narrative experience— anecdotal and other reasons that they are afraid or concerned addressed in SDM.⁴⁴

This contrast between the physician's perception of the role of information in promoting patient autonomy and the other aspects involved from the patient's view highlights that patient autonomy is not defined by informed patients who decide by weighing the pros and cons of medical information, but more personal aspects of one's life also play a major role in reaching a decision. Though some researchers note that preferences regarding information and participation represent components of a single attitude, others have found different correlations.^{34,45} For

example, for patients, the process of involvement in decision-making may be more related to aspects of processes that reach beyond information and factual knowledge, like personality, emotional states, and coping strategy. In a qualitative study with women with breast cancer, Hack et al. found that patients believed that information should depend on the patient's educational status, personality, coping style, and illness severity⁴⁶. This is in contrast to the emphasis placed on information and knowledge by physicians, whose role as well-educated professionals depends on knowing which treatment to recommend.

The contrast between factual, medical knowledge and knowledge of personal preferences and values can complicate the process of shared decision-making. Indeed, Barry & Henderson suggest that the level of preferred involvement in decision-making is dictated by the understanding patients have about their condition and that different forms of knowing by the physician and patient may lead to discordance.¹¹ While different funds of knowledge may form barriers to sharing decision-making, the importance of structural and interpersonal aspects should not be discounted. For example, Joseph-Williams et al. identified factors such as the organization of the health care system, power imbalances between patient and physician, and the physician's ability to communicate as important barriers to patient participation in SDM.⁴⁴ Finally, yet another barrier to participation, one that is related to power imbalances and potential health disparities, may be that patients tend to undervalue their own ability to understand the complex knowledge that physicians are seen to possess and may also undervalue the complementary expertise that they can bring to the SDM encounter.⁴⁴

Perceived choice

Not only must the patient and her physician exchange information in order to employ their unique expertise in the service of reaching a decision, both parties must believe that a choice actually exists. Furthermore, patients are reliant upon their physicians to introduce and describe treatment recommendations and options and so physicians can influence shared decision-making (SDM) before the patient has a chance to become involved. Studies have demonstrated that nearly all patients want to be informed of treatment alternatives and, when more than one treatment alternative exists, want to be involved in treatment decisions. Furthermore, perceiving to have a choice, including the choice not to treat, seems crucial in patients' perception of involvement in SDM.^{17,47} Although some patients see "doing nothing" as "no choice," other patients did not realize that forgoing treatment was an option.^{48,49} Informing patients of all treatment options, including the option not to treat, is a central component of the experience of having a choice.⁴³

Unsurprisingly, the perception of choice can influence patients' preferred role in decision-making. Overall, patients who are offered choices tend to perceive their *actual* role as more active than patients who believe that they were not offered choices. For example, patients undergoing chemotherapy who perceived that they were offered choices were more likely to be actively involved and were satisfied with their level of involvement in decision-making.¹⁶ Other work has also shown that decision-making preference can depend on whether or not patients believed they had a choice and that patients who had options tend to *prefer* an active role.^{50,51} Furthermore, when women were only presented with one surgical treatment option for breast cancer, they tended to perceive that their involvement had not been as active as they had preferred. Therefore, being offered a choice relates to both the way the patient views their

decision-making role and the role that they prefer. This suggests that failure to discuss options may be a driving force in patient's perceptions of discordance.⁵² In this way, some of the benefit attributed to patients taking on an active role in decision-making may actually be linked to the experience of having had a choice. Interestingly, however, Guadagnoli et al. found that the benefits of having been offered a choice between surgical treatments for breast cancer were significant at three months post-treatment, but did not persist at 6 months.¹⁷ Other benefits of being offered treatment options may include more psychological support to patients, which can help patients enact their preferred decision-making role.^{53,54}

In contrast, it is possible that physicians could offer more choices to patients whom they perceive want to be more involved in decision-making. Therefore, there may be a two-way street connecting level of involvement in decision-making and being offered a choice. This is concerning because physicians are not always able to determine their patient's preferred decision-making role.⁵⁵ If physicians tailor the options for treatment that they present based on a perceived level of involvement by patients, those patients who, for various reasons, are perceived to be less actively involved may not even have the chance to deliberate between treatment options. Unfortunately, as discussed later, often patients who are already marginalized in the health care system such as those with less education could be left out the option to share in decision-making because their physicians do not present all the treatment options.

Even if a physician is able to share the information desired by patients and to provide emotional support, she may not be able to accurately assess their patients' preferred decision-making role (DMR).⁵⁶ The difficulty in assessing patient's preferred DMR seems to be unrelated to either the duration of the physician-patient relationship or clinical expertise of the physician.⁵⁷ However, physician communication style is known to influence patients' psychosocial adjustment, decision-making, treatment adherence, and satisfaction with care. Furthermore, communication preferences may vary considerably by age, gender, disease type, stage, and prognosis.⁵⁸ Despite some identifiable trends, information preferences cannot be reliably predicted and Russell et al recommend that physicians regularly ask patients what information they would like to know, who else should be given the information, and how information should be presented.⁵⁹ In summary, information sharing and the provision of a sense of choice among treatment options are both important aspects of shared decision-making that may influence the ways in which patients and physicians participate together in the process. Patient involvement may be influenced the manner in which information is communicated including the feeling of having been offered a choice.

II. Decision making roles (DMRs)

Assessing decision-making roles (DMRs)

An important component to sharing a decision between patient and physician is facilitating participation by the patient to the extent that s/he prefers. Shared decision-making (SDM) is based on respect for patient autonomy and therefore must also be informed by the patient's preferred level of involvement because respect for autonomy cannot be achieved if patients are asked to participate in decision-making that goes against their own preferences. Participating fully in the decision process involves complicated interactions between the patient

and physician in which the physician is expected to determine how much information a patient needs in order to make an informed decision. Patients are then expected to exert their own beliefs and values in deliberating between options.

A crucial step in ensuring that patient autonomy is respected in SDM is understanding the extent to which patients do or do not want to be involved in SDM. One clinically relevant survey tool that has been well-validated in people with cancer is the Control Preferences Scale (CPS) devised by Degner et al. after four years of qualitative work with patients with breast cancer.⁶⁰ The Control Preferences construct aims to describe the degree of control an individual wants to assume when decisions are being made about medical treatment. This concept was borne out of an understanding that decision-making takes place within a social context and is influenced by that context, as opposed to being solely the product of the patient's medical condition and available treatments. Notably, the CPS construct is decidedly separate from patient's preference for information, although it is often used in studies that elicit and describe information sharing and information preferences. Again, it is important to note the role of information sharing in the larger process of SDM and that information sharing alone does not constitute SDM.

The Control Preferences Scale (CPS) asks patients to select their preferred role in decision-making from among five options ranging from active participation (active role) to relinquishing the decision to their physician (passive role). From these five answer options, three groups are constructed – active, collaborative, and passive.⁶¹ The role the patient perceives to actually have played in decision-making can also be measured using the same five answer options and is referred to as the patient's actual role.¹ The CPS scale has been used to study patient decision making in numerous clinical and cultural contexts and has also been used to compare patient and physician perceptions about level of involvement.^{42,51,53,62-69}

Other models of assessing and categorizing patients' decision-making roles (DMRs) have also been used. For instance, Flynn et al. propose a model in which patients are grouped as either deliberative or non-deliberative and subsequently as autonomists or delegators, resulting in 4 combinations of two factors – deliberative autonomists, non-deliberative autonomists, deliberative delegators, and non-deliberative delegators.⁷⁰ Still others have attempted to distinguish between the complexities involved in decision-making by constructing a model in which decision-making is separate from problem-solving (Deber-Kraetschmer Problem-Solving Decision-Making Scale).⁷¹ In using their model to assess patients undergoing angiogram, Deber et al. found that, although patients had a significant desire for information, they overwhelmingly wished the problem-solving tasks to be performed by or shared with their physician and also wanted to be involved in the decision-making tasks required to reach a treatment decisions. This highlights the differences between the concept of information sharing and decision-making and demonstrates that these concepts can be separated ideologically.

¹ Note that the patient's perception of the role they have actually been playing is measured and that no outside assessment of their role is included in the scale. One of the strengths, and also one of the disadvantages of the CPS, is that it is entirely based upon the perspectives of the patient and so is not an "objective" view of decision-making role.

Critiques & shortcomings of the Control Preferences Scale (CPS)

While the Control Preferences Scale (CPS) has been well validated in people with cancer and is easy to use, it is not without its limitations. Some have criticized the CPS for perceived ambiguity in the role choices citing the fact that patients' narrative descriptions of their roles do not always match their preferred CPS role and that patients can have difficulty in choosing the CPS role that fits them best.^{48,72} Furthermore, there have been other critiques of the CPS in that its wording may not align with the theoretical understanding patients have about what it means to "share" a decision and that the Control Preferences Scale (CPS) may over estimate the number of people actually sharing decisions.^{73,74} CPS roles may be complicated by the degree to which patients do or do not think their actions affect their health outcomes. Treatment outcomes may also influence CPS choices and patients may feel anxious about taking on responsibility for decisions that result in adverse outcomes.^{6,75,76} Finally, recent qualitative work has indicated that while patients' conceptual definitions of SDM center around an interactive communication process, patient perception of having participated in a shared decision appear more related to the outcome of a mutually agreed upon patient-physician decision rather than the process through which this decision was reached.⁷³ In this vein, the only common element described by patients asked to define SDM was that the process had ended in a decision that was mutually agreed upon by the patient and the physician – in other words, shared decision-making (process) is not the same as making a shared decision (result of process). Shay et al. therefore conclude that studies attempting to understand the extent to which the patient was engaged in an interactive exchange with the physician may not be able to do so using the Control Preferences Scale (CPS) scale.

Theoretical links between decision-making role (DMR) and outcomes

Assessing patients' preferred and actual decision-making roles (DMRs), as well as the concordance between the two has been the subject of numerous studies because of the links that have been observed between DMR and concordance and physical and mental health outcomes. What are the potential benefits to patients that may derive from being actively involved in shared decision-making? Street et al. describe a model in which patients may benefit both directly and indirectly from being involved in decision-making.⁷⁷ In terms of direct effects of enhanced communication between patient and physician, Street et al. describe hypothetical improvements in health outcomes such as symptom reduction, quality of life, and other physiological measures derived from the therapeutic talk between a physician who validates a patient's perspective and expresses empathy. Benefits may also be indirect in that patients involved in the SDM process may have improved affective-cognitive outcomes such as understanding, satisfaction, and trust, which may then be linked to improved health outcomes via increased satisfaction with care, motivation to adhere, trust in the clinician, self-efficacy, and a shared understanding. Furthermore, patient participation in the consultation may help the physician better understand the patient's needs and preferences, as well as elucidate possible misconceptions that patient may have about treatment options. Figure 1, from Street et al, shows a proposed model to describe the ways in which SDM might be linked to improved patient health outcomes.

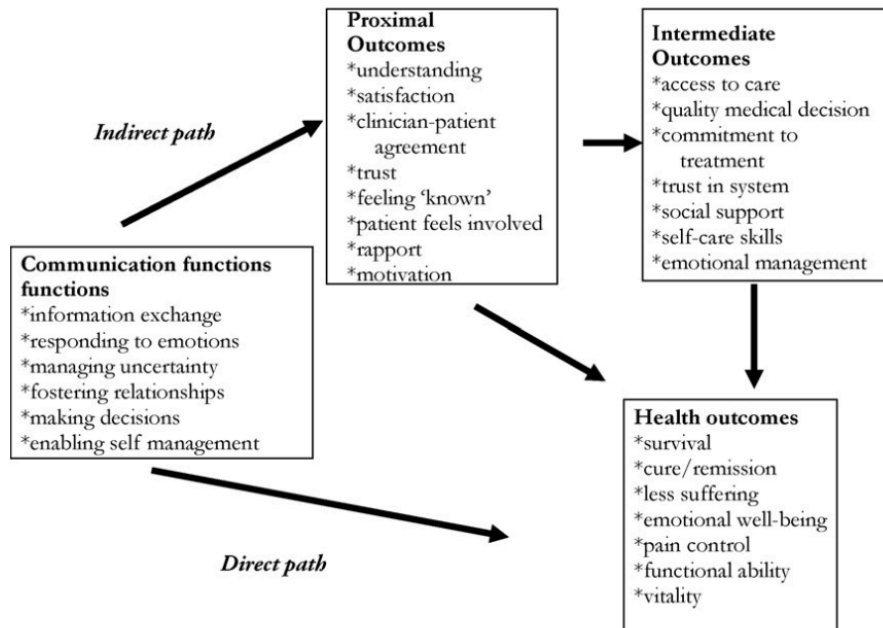


Figure 1. Conceptual framework linking shared decision making (SDM) to patient health outcomes (from Street et al. (2009)).

Measuring outcomes associated with decision-making roles (DMRs)

The general consensus in the literature holds that patients with more active roles and concordant roles have better health outcomes and are more satisfied.^{6,8,9,61} For example, women with breast cancer who indicated having been actively involved in SDM for surgery had significantly higher quality of life at follow-up than women who indicated that they had played a passive role, however the authors caution that causation between active participation and quality of life cannot be drawn.⁷⁸ It is possible that patients who had better quality of life at baseline were better able to be actively involved in their consultations. Likewise, those patients who reported having played a passive role in their treatment consultation may have had lower levels of quality of life at baseline. Other work has shown that patients receiving chemotherapy had lower levels of well being and lower quality of life if they had played a passive role.⁷⁹ However, it is not known what aspects of the passive role disposed these patients to relatively poorer adjustment than their relatively more active counterparts. Results like this have partially driven the push toward adopting SDM and for studying decision-making roles (DMRs).

While patients with active roles seem to be better off in terms of health outcomes, it is unclear whether or not a patient's preferred role or actual role is more important – that is, whether or not it is the level of involvement a patient wants to have or feels they actually have had in decision-making that most impacts outcomes. One study found that patients who preferred a collaborative role pre-consultation and stated that they had assumed an active role (as measured at 12 weeks post-consultation) had significantly higher quality of life and fewer cancer-specific concerns at follow-up than did patients who stated that they had played a passive role.⁴¹ This would seem to indicate that patients with discordant roles were not dissatisfied, but

that the type of role actually played (active vs. passive) impacts quality of life and cancer-specific concerns. In contrast, others have drawn both theoretical and observed connections between concordance and health outcomes. Atherton et al. found that patients who had concordant roles reported better quality of life than those that had discordant roles citing improved adherence to treatment, improved knowledge, self efficacy, and/or self management as potential reasons for the trend.⁶² Therefore, it is not known whether or not actual role or role concordance is the most important predictor of patient outcomes like satisfaction and quality of life. Patient satisfaction may be an increasingly used measure in studies that explore SDM in light of the fact that patient satisfaction is increasingly being used to determine what constitutes a high quality of care. The possibility that patients' role preferences may change over time and may be influenced by treatment outcomes should also be considered.

To address the question of the relative importance of actual role vs. concordance, more recent work has focused on comparing concordance and actual role. Kehl et al. found that patients who report engaging in shared decisions more often report excellent quality of care and rate their physician's communication more positively.⁸⁰ The same study found that the associations between having experienced a shared decision and positive appraisals of quality and communication persisted regardless of the patient's preferred role in decision-making. A handful of other studies have also demonstrated similar findings in that the beneficial outcomes observed in patients who participate actively in decision-making may be most related to patient's actual (self-perceived) roles, rather than on preferred role or concordance between preferred and actual roles. This has led some authors to suggest that even patients who express a preference for a more passive role should be encouraged, though not coerced, into participating more actively in decision-making as this is likely to benefit them.^{80,81} However, as Kehl et al. note, it may be possible that passivity is a risk factor for emotional distress and caution that interventions designed to persuade patients to be more active might backfire.⁸⁰ Given the fact that patients' actual role may be most predictive of certain outcomes like quality of life and impression of physician communication, it will be increasingly important to find ways to engage patients actively in SDM while simultaneously allowing for individual variability and comfort level in participation. To engage patients actively, however, physicians must first understand the factors that may influence the ability to share in the decision-making process.

Changing preferences over time

Not only may individual differences between patients in terms of preference for involvement influence the extent to which they participate in shared decision-making, longitudinal trends and change in the patient-physician dynamic may also impact role preference. In looking at the changes in role preference over time, the degree to which patients prefer to participate in decision-making has likely changed over the past decades. In their review of studies using the Control Preference Scale in populations of people with cancer over the past 30 years, Chewing et al. found that in later studies (published 2000 or later), more patients (86%) preferred to participate rather than delegate decisions compared to patients in published before 2000 (54% preferred to participate rather than delegate).¹⁵ The trend toward patient-centered care will likely continue to influence patient decision-making roles.

III. Participation in SDM as a coping strategy

Coping strategies

Coping is the process of managing internal and external demands which are appraised as taxing or exceeding the resources of the individual.⁸² Coping and participation in decision-making are theoretically linked in that some patients may use involvement in decision-making as a coping response to perceived threats, challenges, and harms associated with cancer and treatment.⁶⁹ Certain coping strategies such as those low in avoidance have been associated with better adjustment and a preference for a more active decision-making role (DMR).⁸³ Furthermore, repressive coping may moderate the positive relationship between active DMR preference and improvement in health related quality of life.⁶⁹ Coping styles such as problem-solving and reliance on social support, as well as those low in emotional avoidance, have been correlated with more positive adjustment to cancer.⁸³ Further work on the potential links between coping style, DMRs, and other patient factors is needed to better understand the complexities of the relationship between coping and involvement in decision-making.

Problem-focused coping

Receiving a cancer diagnosis and preparing to make treatment decisions can be an especially stressful period for patients. According to Lazarus and Folkman's cognitive theory of stress and coping, when interactions with the environment are appraised as stressful, coping is required to regulate distress (emotion-focused coping) or to manage the problem causing distress (problem-focused coping).⁸⁴ Problem-focused coping includes strategies for gathering information, decision-making, planning, and resolving conflicts and has been shown to be related to positive affect. For some patients, the use of problem-focused coping strategies that include active involvement in shared decision-making (SDM) may be a coping response to perceived threats, challenges, and harms associated with cancer and treatment.⁶⁹ However, while some patients may consider being actively involved in SDM as a challenge, others may perceive involvement in treatment decisions as a burden.⁸⁵ Furthermore, coping style may change throughout the disease and treatment trajectory as the appraisal of threat varies according to the stage of the disease and its treatment.⁸² The potential links between coping and involvement in decision-making require further investigation.

Coping & information

Much of the research into patient's preferred and actual roles in decision-making has focused on the role of information exchange and information seeking in the decision-making process. Again, the potential links between coping and involvement in decision-making are strong. Information seeking, a type of problem-focused coping strategy, is the most frequently used method to cope with and maintain control over a stressful life event. Information seeking is a multifaceted endeavor, involving not only the information gained through seeking, but also the process of seeking the information itself. Previous work has demonstrated that both aspects of information seeking are important in the process of decision-making for some patients with

cancer. For instance, a qualitative study with women with breast cancer found that women wanted their physician to ask them if they wanted to know certain information about their disease, thus indicating that the women had a desire to control the flow of information.⁸⁶ Therefore, the way that patients cope with their diagnosis may be related to the amount and type of information they desire.

In addition to the potential links between coping and desire for information, the degree to which patients are informed may influence their preferred decision making role. Information exchange and information seeking behavior have been linked with decision-making roles (DMRs) in that more informed patients tend to prefer an active or collaborative role compared to those patients who were less informed.⁴¹ Davison et al. also found that men with prostate cancer who were assisted to get to the information they wanted assumed a significantly more active role in SDM and had lower levels of anxiety. This points to the possibility that receiving the type and amount of information one wants is an empowering force.⁵⁴ Feeling informed and being satisfied with physician communication have been found to be more strongly associated with patient involvement in decision-making than overall mood or quality of life.⁴¹ Therefore, just as the perception of choice may influence patients' preferred DMR, so too may the extent to which patients feel informed. Information seeking, in turn, may be related to how patients cope with their disease.

Locus of control

One aspect of the relationship between coping and involvement in decision-making is the perception of a sense of personal control, treatment options, and disease. Taylor and Brown define a belief in personal control as integral to an adult's sense of safety, self-concept, self-esteem, and maintaining a non-depressed mood. The desire to become involved in shared decision-making (SDM) varies among patients and appears to be related to the approach patients take to the decision problem and the amount of control they prefer.²⁶ While some people discover a new sense of personal control through re-examining their identity during and after cancer treatment, others may tend to relinquish control preferring the safety provided by a figure of authority, such as a physician.⁸² Some patients with cancer prefer to be actively involved in treatment decision-making because doing so affords them control over their body, health, and life.⁴⁶ Similarly, when interviewing patients with cancer who had refused treatment, van Kleffens et al. found that an important component in making decisions was the personal initiative that playing an active role represented.⁴³ Therefore, preferred decision-making role may relate to the degree of control a patient prefers to have in the process and participation in SDM may be one way patients maintain or regain control during illness.

Although it is evident that active involvement in decision-making may contribute to a sense of personal control, qualitative work has shown that some patients who take on a passive role do not view this as a loss of control. Instead, for some patients who prefer a passive DMR, handing control over to medical professionals may be a positive coping strategy.⁸⁷ Additionally, Hack et al. found that patients who preferred a passive role also wanted to be informed about the treatment plan, but expressed that it was important to place trust in their physicians as experts.⁴⁶ These findings demonstrate that a desire for personal control and desire to participate in the decision-making process are not equivalent.

IV. Factors associated with patient's decision-making role (DMR)

Demographic factors

The literature seems to show a general consensus that certain demographic features tend to be related to patient's decision-making role (DMR). For example, women and younger people tend to prefer a more patient-directed approach to shared decision-making (SDM).^{47,51,69,70,86,88,89} In addition to the relationship between age and preferred role, age and generational expectations of involvement in medical decision-making may influence perception of actual DMR. For example, when compared to older women, younger women with breast cancer were more likely to report that they had played a more passive role than preferred.⁵² As the relationship between patient and physician has moved away from a paternalistic dynamic, patients may have come to expect to be more involved in treatment decisions and may therefore feel that their role was too passive when these expectations are not met.

Education is another demographic component that has been shown in numerous studies to be positively correlated with preference for a more active DMR.^{13,38,46,53,69,70,90} Further, education seems to impact whether or not a patient realizes her preferred DMR and the direction of discordance. In one study, women with breast cancer who were less educated actually played a more active role than they would have preferred, indicating that education level may influence self-perceived capacity to participate in SDM.⁵² Reasons for this may relate to the finding that patients with lower education who preferred a passive role felt that they lacked knowledge that they considered essential for making informed treatment decisions.⁴⁶ Though the interaction between level of education and preferred involvement in decision-making is undoubtedly complicated and may be related to perceptions of judgment and stigmatization by one's physician, it is imperative to find ways to involve patients of all levels of education in decision-making about medical treatments in a manner that is concurrent with their values.

Since SDM relies so heavily on the exchange of complicated medical information, it is likely that a patient's level of education and comfort with the medical system plays an important role in perceived ability to be involved and to contribute to decision-making. However, some have speculated that education may actually be conflated with age and that, in one study, younger patients tended to have more education than older patients.⁹¹ This assertion, however, was weakened by subsequent work done by Cassileth et al., who found that the relationship between increased age and preference for a passive role was significant even when education level was kept constant.³⁴ Therefore, it is likely that generational influences and perceptions about the nature of the patient-physician relationship, as well as individual's level of education may influence preferred decision-making roles.

Other demographic features that have been previously investigated in relationship to decision-making roles (DMRs) among people with cancer, are living arrangements, marital status, and income. With regards to living arrangement, patients (including those with cancer) were more likely to prefer an active role when living alone compared to those who lived with another person (either a child or another adult).⁹⁰ There is discrepancy in the literature with regards to the nature of the relationship between marital status and preferred DMR with some showing that married men prefer a passive role, while others showing that married women prefer an active or collaborative role.^{92,93} As these data indicate, however, gender may play a role in the relationship between marital status and preferred decision-making role. Still others have shown no correlation between the marital status and preferred role.⁹⁴

Overall, the literature lacks information about the relationship between socioeconomic factors and DMR, which, due to perceived and actual power differences between physician and patient, may be related to the manner in which patients experience health care interactions and therefore to the level of involvement in decision-making patients are comfortable with. Authors have suggested that more work needs to be done to better describe any relationships between socioeconomic status, ethnicity, and DMR.²⁶

Clinical factors

Data relating clinical factors and patients' decision-making roles (DMRs) tend to show that patients with poorer general health, more advanced disease stage, lower physical functioning, and more comorbidities prefer a passive DMR.^{56,60,62,95,96} Other factors that have been studied include type of cancer and disease stage.

Although most studies focus on the decision-making roles of patients with a single type of cancer, a few studies have compared patient's DMRs by cancer type. Most of the studies looking at patients with different types of cancer were inadequately powered to uncover meaningful relationships between disease type and DMRs.^{6,34,45,55} One study, however, which sought to analyze patients DMRs in terms of cancer type found that people with breast or prostate cancer were more likely to prefer a shared or active role when compared to people with lung, hematologic, gastrointestinal, or head and neck cancer.⁹⁷ As breast and prostate cancer have received more public attention than the other cancer types, Shields et al. hypothesize that greater public awareness and the wealth of available information about these cancers might foster a sense of greater activism on the part of the patient. Other factors that may be involved include more treatment options for breast and prostate cancer as compared to the other types of cancer studied and a general sense that participation in treatment decisions might be expected for patients.

In terms of other disease-related factors, there does not appear to be consensus about the role of cancer stage in preferred decision-making role (DMR). While Degner et al. found that women with breast cancer in earlier stages of disease preferred a more active role in decision-making, Davison et al. found that men with prostate cancer preferred a passive role – again raising the possibility that decision role preference may be influenced by aspects such as gender, type of cancer, and historical efforts to include patients in decision-making.^{92,93} A recent meta-analysis concluded that preferred role was not significantly related to tumor stages, but that actual role was related to tumor stage with patients in stages 0 to 2 being more likely to actually experience an active role.⁹⁸ This is particularly interesting because it seems to indicate that patients who are less ill tend to be more actively involved in decision-making, but that they may not prefer this role. Again, it is not known whether preferred role, actual role, or concordance between the two is the most important predictor of the patient outcomes ascribed to shared-decision making.

Decision-making role and physical functioning have also been studied. With regard to physical functioning, patients who actually played active role had higher physical functioning scores (as measured by the SF-36).⁶² A similar relationship between higher Karnofsky performance scores and more active involvement has also been shown.⁹⁹ Taken together with the data about disease tumor stage, which seems to indicate that patients with more progressed disease play a more passive role, there seem to be conflicting associations between preferences

for more vs. less involvement in decision-making over the progression of illness. Multiple factors are likely at work in changing preferences including the evolving experience of what it means to patients to be ill, progressing disease, development of longitudinal relationships with physicians and other caregivers, and the effects of treatment. To this end, Say et al. note that it is difficult to disentangle experience of care from the experience of ill health and that physician behavior may be equally implicated in patients' changing preferences as the characteristics and experiences of patients themselves.¹⁰⁰

Finally, difficulty in accepting a diagnosis of cancer may make it difficult for patients to participate actively in decision making.⁴⁶ As Say et al. note, this offers a possible explanation for why, in their study, patients' preferences for involvement may increase over time and as experience with illness evolves.¹⁰⁰

Psychological factors

Though the process of decision-making is undoubtedly unique to each individual and is too complex a concept to measure completely, describing the psychosocial factors that may be related to preferred and actual decision-making role (DMR) can help physicians and patients begin to understand the complex milieu of shared decision-making (SDM) and the way that information gets incorporated into personal experience. Several psychosocial factors, such as resilience, depression, anxiety, and quality of life have been related with patients' preferred and actual roles in decision-making.

Resilience

Resilience has become a factor of interest in assessing patients' distress related to cancer diagnosis and treatment and is considered to be the most common outcome following exposure to potential trauma.¹⁰¹ Previous work has shown a positive relationship between resilience and comfort with decision-making. Women with breast cancer who were more resilient had less difficulty in making treatment-related decisions than women with lower levels of resilience. Furthermore, more resilient women had lower levels of symptom distress immediately following surgery and lower levels of psychological distress when measured 8 months post-surgery. To date, few studies have directly measured patient resilience as it relates to decision-making.

Depression

Depression has been shown to be related to patients preferred and actual DMRs. Higher levels of depression appear to correlate with preference for a more passive role.⁵⁰ Furthermore, passive involvement in SDM is significantly associated with poorer emotional adjustment.⁷⁹ Others have shown no relationship between DMR and psychological disease.³⁸ Conversely, it has been hypothesized that patients suffering from depression may prefer to leave the responsibility of deciding about treatment options to their physician. While depression may or may not be related to decision-making role, levels of psychological distress have not been shown to be significantly related to concordance.¹⁰²

Regarding chemotherapy specifically, work by Hack et al. showed that people with breast or prostate cancer who received chemotherapy were more likely to have greater mood disturbance (higher negative and lower positive mood scores) than people with breast or prostate cancer who did not receive chemotherapy.⁷⁹ Interestingly, the relationship between receipt of

chemotherapy and negative mood state was only significant for women who had played a passive role in decision-making and not for women who played a collaborative or active role. These findings may indicate that passivity can be a risk factor for emotional distress and Hack et al. suggest that patients who prefer to take on a passive DMR may be assisted through tailored psychosocial and educational outreach to address the origins of the avoidance behavior and associated distress. Kehl et al. also posit that passivity is a risk factor for emotional distress.⁸⁰ The relationship between treatment and psychological distress and decision-making roles requires further investigation.

Anxiety

In contrast to patients with depression who may tend to prefer a more passive role, Vogel et al. found that patients with higher levels of anxiety tended to prefer a collaborative role and those with lower levels preferred an active role.⁵⁰ The same study also found that patients who reported actually playing an active role decision-making role had both higher tension and anxiety scores, but also higher vitality scores.⁶² Along the same lines, Atherton et al. later found that more anxious patients also actually played an active role.⁶² In comparing the findings of Vogel and Atherton, it is worth noting that more anxious patients tended to prefer a collaborative role and that more anxious patients felt they had actually played an active role. This may be important because anxiety levels may influence patients' perceptions of their level of involvement in SDM. Unfortunately, there is no way to assess the relationship between preferred role and actual role across two datasets. Although Atherton et al. did not assess the potential relationship between concordance and anxiety, it could be that playing a role more active than preferred contributes to higher levels of anxiety.

Personality

One of the unresolved questions in the literature regarding decision-making role (DMR) is that of how it changes with time and illness progression. Assessing DMR as it relates to personality may help elucidate whether or not DMR is a type of inherent trait that does not shift with time or whether it is more related to other varying factors such as health status or disease progression. According to Gattellari et al., preferences for involvement in decision-making may stem from an underlying personality trait-like belief about the degree to which one's behavior controls one's health care.⁸¹ More work relating decision-making roles and personality is needed to better understand if a link exists between these two factors.

The literature that does exist indicates personality and decision-making role may be related. Based on the connection between repressive coping strategy and passive decision-making role, it has been hypothesized that an anxious-reserved personality may drive some individuals to withdraw as an attempt to adapt to stressful situations.⁶⁹ For example, among a group of women with breast cancer, Hyphantis et al. found that active decisional preference predicted improvement in physical health-related quality of life only in women with lower levels of repression.⁶⁹ Still other personality traits like optimism may help predict patient's ability to cope with cancer treatment decision-making – serving as a potential link between coping strategy, personality, and decision-making role.⁴² While decisional passivity does not inherently yield unfavorable consequences, it may compromise well-being through a mechanism moderated by certain personality traits like the defense of repression.⁶⁹ Again, further work is required to determine the extent to which personality may be related to decision-making role.

V. Justification for my study

Ethical concern to involve patients in their health care decisions has been followed by a complex array of empirical studies suggesting that both patients' decision-making role (DMR) and the concordance between their perceived role and their preferred role may influence quality of life after cancer treatment. However, there is no one clear preferred model for patient's roles and it has been suggested that there may be mediating factors like resilience, coping style, and personality. For example, while an active role is often associated with better outcomes, for some patients who prefer a passive role, an active role may increase their anxiety. Furthermore, there is evidence that physicians are not always clear about how to elicit patient preferences, how to share decision-making, and how to communicate. To this end, physicians may feel overwhelmed if presented with too vague and global a task to encourage patients to play the role they prefer, so a need exists to clarify which factors are most valuable to patients. It is also unclear which contextual, malleable conditions might help patients play the role they prefer.

Given the ethically- and empirically-based implications of involving patients in medical decision-making, further describing the factors associated with patients' preferred DMR is an important step toward helping patients and physicians engage with each other. While several previous studies using the Control Preference Scale (CPS) have shown that certain demographic factors (namely age and education level) and some psychosocial and clinical variables are related to patient's preferred and/or actual roles in decision-making, this study will be unique in that it will incorporate all three types of factors (demographic, psychosocial, and clinical) to generate a more complete understanding of the complex milieu of SDM from the perspective of the patient. Insufficient literature exists that compares patients' DMRs with factors such as hope, coping style, income, pain and personality – all of which will be analyzed in this study. Furthermore, this study will allow for comparisons to be made with respect to different types of cancer as study participants had breast, lung, colon or gynecological cancer. The aim in conducting this study is to not only describe more fully the various factors that may be related to DMRs, but also to analyze the potential construct validity of the Control Preferences Scale (CPS) itself.

VI. Measures used in this study

While it is difficult to assess an abstract concept, such as quality of life, from a single question, the scales used in this study have been well-validated among patients with cancer and are used throughout the literature.¹⁰³ Though multi-item scales, such as the measures used in this study, cannot always address the complexities of the constructs for which they are designed, quantitative work such as the forthcoming paper is an important starting point for understanding some of the factors involved in the process of shared decision-making in cancer treatment.

METHODS

Patients and Settings

This study is part of an ongoing, longitudinal study of the symptom experience of oncology outpatients receiving chemotherapy.¹⁰⁴ Eligible patients were aged ≥ 18 years; had a diagnosis of breast, gastrointestinal, gynecological, or lung cancer; had received chemotherapy within the preceding 4 weeks; were scheduled to receive at least 2 additional cycles of chemotherapy; were able to read, write, and understand English; and provided written informed consent. Patients were recruited from 2 comprehensive cancer centers, 1 Veterans Affairs hospital, and 4 community-based oncology programs. Eligible patients were approached by a research staff member in the infusion unit to discuss participation in the study. Written informed consent was obtained from all participants. The study was approved by the Committee on Human Research at the University of California at San Francisco and by the Institutional Review Board at each of the study sites.

Instruments

A demographic questionnaire obtained information regarding age, sex, ethnicity, education, and income. Medical records were reviewed for disease and treatment information. Patients were asked to report on their symptom experience for the week before the administration of the next cycle of chemotherapy.

Decision-making role

The CPS scale has been used to study patient decision making in numerous clinical and cultural contexts and has also been used to compare patient and physician perceptions about level of involvement.^{42,51,53,62-68,105} The CPS has been widely used in patients with cancer to assess decision-making role with regard to patient satisfaction,⁸⁰ trust in physician,¹⁰⁶ and other demographic and clinical features.⁹⁸

The Control Preferences Scale (CPS) assessed patient's self-reported decision-making role with respect to their cancer treatment, both in terms of role they preferred to play, and role they actually were playing. Responding to the prompt "select the phrase that most closely matches the role you have actually been playing in dealing with your cancer diagnosis," patients selected their actual role from among five options ranging from make decisions with little/no input from the doctor; make decisions after seriously considering my doctor's opinion; doctor and patient make decisions together; doctor makes decisions after seriously considering the patient's opinion; and doctor makes decisions with little/no input from patient (Figure 1). Patients then selected their preferred role ("the role they would have preferred") from among the same five options.

Based on the work of Degner¹⁰⁷ and others,^{88,95,106,108} to facilitate comparisons across the decision-making roles, we collapsed the five preferred roles into three, as follows: Active, Collaborative, and Passive. Because of high degree of concordance between patients' preferred and actual role, for the purposes of this study, we limited our analysis to patients whose actual role matched their preferred role.

Functional status

The Karnofsky Performance Status (KPS) scale evaluated self-reported functional status. The KPS scale ranges from 30 (“I feel severely disabled and need to be hospitalized”) to 100 (“I feel normal; I have no complaints or symptoms”).²⁷ KPS measures overall physical status and has been shown to accurately predict early death in patients with cancer.¹⁰⁹

Comorbidity

The Self-Administered Comorbidity Questionnaire (SCQ) was used to measure comorbidity. This questionnaire consists of 13 common medical conditions, described in lay terms. Patients indicated if they had the condition, if they had received treatment for it, and if it limited their activities, resulting in a maximum of 3 points for each condition. Total scores can range from 0 to 39. The SCQ has well-established validity and reliability and has been used in studies of patients with a variety of chronic conditions.^{110,111}

Cancer- or cancer treatment-related symptoms

The Memorial Symptom Assessment Scale (MSAS) was used to evaluate the occurrence of cancer- or cancer treatment-related symptoms¹¹². The MSAS contains a list of 32 symptoms that may occur as a result of cancer treatment. Patients were asked to rate whether or not they have experienced the symptom in the past week. If they had experienced the symptom, they were asked to rate its severity, frequency, and level of associated distress. The validity and reliability of the MSAS is well-established.^{113,114}

Coping

General coping was assessed with the Brief COPE, a 28-item self-report measure.¹¹⁵ The Brief COPE has been used in numerous studies examining coping style and related correlates and outcomes, including studies involving people with cancer¹¹⁶⁻¹¹⁸, and is examined in this study in terms of 14 two-item subscales, as recommended by Carver.¹¹⁵ The Cronbach’s alphas for the sample were 0.75 (active), 0.74 (planning), 0.79 (positive reframing), 0.68 (acceptance), 0.84 (humor), 0.92 (religion), 0.77 (emotional support), 0.76 (instrumental support), 0.46 (self-distraction), 0.72 (denial), 0.65 (venting), 0.87 (substance use), 0.57 (behavioral disengagement), and 0.73 (self-blame).

Cancer-specific coping

The Mental Adjustment to Cancer (MAC) scale, a 40-item self report scale, assessed cancer-specific coping.³¹ The MAC has been shown to be reliable and acceptable in patients with cancer.³¹ Each statement is rated on a scale from 1 (“Definitely does not apply to me”) to 4 (“Definitely applies to me”). Scores for each of the five validated MAC subscales (i.e. Fighting Spirit, Anxious Preoccupation, Fatalism, Hopelessness/Helplessness, and Avoidance) were computed.¹¹⁹ Extensive validity data are available for the MAC.^{120,121} The Cronbach’s alphas for the sample were 0.81 (Fighting Spirit), 0.62 (Anxious Preoccupation), 0.80 (Helpless/Hopeless), 0.53 (Fatalism) (the Avoidance subscale consists of only 1 item, therefore a Cronbach’s alpha was not calculated).

Personality

Personality factors were assessed using the NEO-Five Factor Inventory (NEO-FFI), a standard, validated questionnaire of personality that has been widely validated and has excellent

psychometric properties.¹²² The NEO-FFI consists of 60 statements covering five broad dimensions of personality: neuroticism (i.e. the tendency to experience distressing emotions such as fear, guilt, and frustration), extraversion (i.e. the disposition toward cheerfulness, sociability, and high activity), openness to new experiences (i.e. the tendency to have a receptive orientation toward varied experiences and ideas), agreeableness (i.e. the inclination toward interpersonal trust and consideration of others), and conscientiousness (i.e. the tendency toward persistence, sense of duty, organizing, planning, and self-discipline). Each statement is rated on a 5-point scale ranging from 1 (strongly disagree) to 5 (strongly agree), resulting in a possible score of 12 to 60 for each of the five personality dimensions. The NEO-FFI has been extensively used in studies of psychological functioning and behavior and has also been shown to predict fatigue in women with breast cancer.¹²³ The Cronbach's alphas for the sample were 0.87 (Neuroticism), 0.80 (Extraversion), 0.77 (Openness), 0.76 (Agreeableness), and 0.84 (Conscientiousness).

Depression

The Center for Epidemiologic Studies Depression Scale (CES-D), which consists of 20 items representing the major symptoms in the clinical syndrome of depression, was used to assess depression. Possible scores range from 0 to 60, with scores ≥ 16 indicating the need to evaluate the patient for major depression.¹²⁴ The CES-D has been validated in patients with cancer.¹²⁵ The Cronbach's alpha for the sample was 0.89.

Anxiety

Anxiety was assessed with the Spielberger State-Trait Anxiety Inventories (STAI-T and STAI-S) each consisting of 20 items, rated from 1 to 4, with a resulting range of 20 to 80 for each of the two scales. Cutoff scores of > 31.8 and > 32.2 indicate high levels of trait and state anxiety, respectively.¹²⁶ The STAI-S and STAI-T inventories have well-established validity and reliability.^{126,127} The Cronbach's alphas for the sample were 0.92 (trait anxiety) and 0.96 (state anxiety).

Resilience

A 10-item version of the Connor-Davidson Resilience Scale (CD-RISC) assessed resilience.¹²⁸⁻¹³⁰ Responses are self-reported on a 5-item Likert scale with responses ranging from "Not true at all" to "True nearly all of the time"). Higher scores indicate greater resilience. The Cronbach's alpha for the sample was 0.90.

Cancer-specific distress

The Impact of Event Scale-Revised (IES-R) is a 22-item instrument that assesses subjective distress in response to stressful or traumatic events—here, the diagnosis and treatment of cancer.¹¹² Three subscales ("intrusion," "avoidance," and "hyperarousal") are calculated based on self-reported 5-point Likert scale responses ranging from 0 ("not at all") to 4 ("extremely"). A mean total score and mean subscale scores are calculated. Internal consistency and test-retest reliability are high for both subscale and cumulative scores¹³¹, and the measure has been used in numerous studies involving cancer patients.¹³²⁻¹³⁴ Cronbach's alpha for the IES-R total score in this sample was 0.92.

Data Analysis

Data were analyzed using SPSS version 22 (IBM, Armonk, NY). Descriptive statistics and frequency distributions were calculated for demographic and clinical characteristics. Analysis of variance (ANOVA), Chi Square tests, and Kruskal-Wallis tests with Bonferroni corrected post hoc contrasts were used to evaluate for differences among the patients based on their preferred and actual decision-making roles. For all analyses, a p-value of < 0.05 was considered statistically significant. All calculations used actual values and adjustments were not made for missing data. Missing data was assumed to be random and so missing observations were simply deleted. Therefore, the cohort for each of these analyses was dependent on the largest set of complete data among the decision-making role groups.

RESULTS

Overall sample

A total of 1553 patients were approached and 941 consented to participate (60.6% response rate). The major reason for refusal was being overwhelmed with their cancer treatment. Of the 941 participants, 862 completed the CPS. Of these, 765 (88.7%) were concordant in terms of their actual and preferred roles and were included in this analysis. Throughout this paper, “preferred role” refers to those patients whose preferred role matched their actual role and so is synonymous with the later. The majority of patients preferred the collaborative role (56.3%), with fewer patients preferring either the active (23.3%) or passive (20.4%) role (Table 1).

Differences in demographic and clinical characteristics

As shown in Table 1, patients who preferred the passive role were more likely to be older, less educated, and have a lower income. Decision-making role did not differ significantly by gender or ethnicity.

Decision-making role varied significantly by cancer type. Patients who preferred a passive role were more likely to have lung or GI cancer than breast cancer. When compared with patients who preferred an active role, patients who preferred a collaborative role had more comorbid conditions. Decision-making role did not vary significantly by KPS score, number of metastatic sites, or years since diagnosis.

Differences in physical and psychological symptoms

Patients who played a collaborative role were more likely to report pain compared to those who preferred an active role (Table 2). Decision-making role groups did not vary significantly with regard to depression, state, or trait anxiety (Table 2).

Differences in psychosocial adjustment characteristics

Table 3 shows the relationship between decision-making role and resilience and levels of fatalism. Compared to those who preferred a collaborative role, patients who preferred a passive role were less resilient. Of all three groups, patients who preferred a passive role had the highest levels of fatalism. Decision-making role varied significantly by coping style with patients who preferred a passive role being less likely than those who preferred an active or collaborative role to utilize the following coping strategies: active coping, planning, positive reframing, and humor. Furthermore, patients who preferred a passive role were less likely than those who preferred a collaborative role to utilize emotional or instrumental support-oriented coping strategies. In terms of personality, differences in decision-making role were significantly related to only one of the five personality dimensions—i.e., patients who preferred a passive role had lower levels of Openness to Experience compared to those who preferred an active role. Lastly, patients who preferred a collaborative role reported lower levels of positive adjustment compared to those who preferred an active role.

DISCUSSION

Several new findings emerged from this study, particularly with respect to the relationship between psychosocial adjustment characteristics and decision-making roles in oncology patients undergoing CTX. Compared to those who preferred an active role, patients who preferred a passive role were less likely to use adaptive coping strategies and had a less open personality.

Patients with a preference for a passive role tended to have a more fatalistic stance, which is consistent with work by Shields and colleagues.⁹⁷ While the term “fatalism” has evoked a negative connotation in the past, recently the construct it represents was re-conceptualized as having both positive and negative valences.^{135,136} For instance, “fatalism” can take the form of acceptance (e.g., “I’ve put myself in the hands of God”), reframing (e.g., “I’ve had a good life, what’s left is a bonus”), or, negatively, as a lack of control or self-efficacy (e.g., “I feel I can’t control what’s happening to me.”). Instead of a resignation to a predetermined fate, adopting a fatalistic attitude may be a logical response to previous poor health outcomes personally or in one’s community.¹³⁶ In this way, the relationship between fatalism and preference for a more passive role may be influenced by patients’ past experience with health and disease and may serve as a mechanism by which patients cope with navigating the cancer treatment process. By evaluating these factors in the same sample, this study adds to our understanding of the relationships between decision-making role and coping strategies, fatalism, and personality.

In addition to a more fatalistic stance, those patients who preferred a more passive role tended not to employ a humor-based coping strategy – to our knowledge, a previously unreported finding. Humor is generally seen as an adaptive coping mechanism and has been associated with positive psychological changes following a diagnosis of cancer.¹¹⁵ This finding, along with the other data from this study, suggest that patients who prefer a passive role may employ less adaptive coping strategies.

The relationship between decision-making roles and coping suggests that the degree of involvement in decision-making may be a manifestation of the patient’s typical (or most prominent) coping mechanisms. The finding that decision-making preferences are closely associated coping styles suggests, as Singh noted previously, that underlying traits may be more responsible for enduring decision-making styles.⁹⁸ Thus, overemphasizing the “active” role may be rooted in mistaken assumptions about the malleability of decision-making styles. While our data suggest that decision-making role preference may be more of a trait-like characteristic, little is known about whether individuals’ decision-making role preferences change over the course of illness. To address the role of time and disease course in decision-making role preference, longitudinal prospective studies should be done.

Our findings are consistent with previous work that found that older age and lower education were associated with preference for a passive decision-making role.⁹⁸ However, this study contributes a slightly different impression of the preferences of oncology patients with regard to decision-making role. Compared with a pooled analysis with data of 3491 patients⁹⁸, in our study a higher percentage of patients preferred a collaborative role (56% in our study vs. 34% in Singh et al.) and more of them (90% vs. 84%) actually played their preferred role. It is possible that the higher percentage of patients who played a collaborative role and the level of concordance between preferred and actual role in our study was influenced by changing expectations for involvement and an increasing emphasis on shared decision-making in health care.⁹⁷ Higher education is known to be related to a preference for a more active role,⁴⁶ so it is

possible that the higher than average level of education of this sample affected these findings. Furthermore, unlike previous research, our study found no significant relationship between gender and decision-making role preference.⁹⁸

With regard to clinical characteristics, preferred decision-making role was associated with the type of cancer and number of comorbidities. Consistent with a previous report⁶³, our study found that breast cancer patients were more likely to play a collaborative role than patients with other cancer types. Shields et al. hypothesized that greater public awareness and the wealth of available information about breast cancer may help foster a sense of greater activism in these patients.⁹⁷ Patients with more comorbidities were more likely to prefer a passive role. However, differences were not found between preferred role and number of metastatic sites. These previously unstudied relationships suggest that one's current health status, rather than stage of disease, may be more important in determining patients' level of involvement or support needed. Further investigation into the role that overall functioning versus disease severity plays in shared decision-making is warranted.

Limitations of this study include data from a single time point, which prevents longitudinal inference. Future studies should collect data about decision-making roles over time to identify trends in how the progression of treatment and/or illness, relationships with clinicians, and other factors may be related to a patient's preferred role. Despite the fact that this study included a sample recruited from six different sites, the patients tended to over-represent some demographic groups. The majority of patients in this study were highly educated, had a high income, were Caucasian, and had breast cancer. These characteristics suggest that our findings may not be generalizable, therefore, further work is needed to identify and address disparities and barriers to participation in shared decision-making by underserved groups, including those not represented by the current sample.

In conclusion, this study underscores that while demographic characteristics, including education, income, and age are related to decision-making role, predicting patients' preferences for involvement in decision-making is complex. Given the potential benefits of playing a more active role⁶, it is important that clinicians find ways to engage all patients in the decision-making process while not abandoning those who prefer a passive role by overemphasizing patient autonomy. Clinicians should be aware that some patients might cope with their illness by seeking support and by playing a less active role in decision-making. These preferences may be influenced by fatalism, personality, coping style, illness factors, culture, and demographics – indicating that decision-making role preference is a complex and multifaceted entity. Clinicians should individualize their approach, finding ways to engage all patients in decision-making to the extent that patients feel supported and valued, while maintaining awareness that participation in shared decision-making could be a way for patients to cope with and understand their illness. Further study is warranted to explore the ways in which decision-making role may change with time and to determine if role or coping style may be influenced by interventions designed to teach adaptive coping skills.

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APPENDIX

Table 1. Demographic and Clinical Characteristics by Decision-Making Role among Patients with Concordant Roles (n = 765).

Characteristic	Active (1) n = 178 23.3%	Collaborative (2) n = 431 56.3%	Passive (3) n = 156 20.3%	Statistics
	Mean (SD)	Mean (SD)	Mean (SD)	
Age (years)	53.7 (11.8)	57.6 (11.1)	58.9 (12.5)	F = 9.9; p < 0.001 1 < 2 and 3
Education (years)	16.7 (3.1)	16.3 (3.0)	15.8 (3.0)	F = 4.1; p = 0.017 1 > 3
Karnofsky Performance Status score	80 (11.7)	81 (12.3)	80.1 (12.1)	F = 0.2; p = 0.654
Number of comorbidities	2.2 (1.4)	2.5 (1.4)	2.4 (1.3)	F = 3.2; p = 0.040 1 < 2
Self-administered Comorbidity Questionnaire score	5.2 (3.1)	5.7 (3.2)	5.3 (2.8)	F = 2.1; p = 0.122
Avg. time since cancer diagnosis (years)	2.0 (3.4)	2.3 (4.2)	2.0 (3.6)	F = 0.4; p = 0.673
Median time since cancer diagnosis (years)	0.44	0.45	0.43	
No. of prior cancer treatments	1.9 (1.5)	1.7 (1.5)	1.6 (1.6)	F = 0.4; p = 0.660
No. of metastatic sites including lymph node involvement	1.2 (1.3)	1.2 (1.2)	1.4 (1.3)	F = 1.6; p = 0.212
	% (N)	% (N)	% (N)	
Gender				
Female	81 (144)	80 (343)	71 (111)	$\chi^2 = 5.8$; p = 0.056
Male	19 (34)	20 (88)	29 (45)	
Ethnicity				
White	74 (131)	72 (201)	66 (100)	$\chi^2 = 3.4$; p = 0.764
Black	6 (10)	7 (30)	9 (14)	
Asian or Pacific Islander	10 (18)	12 (49)	14 (21)	
Hispanic Mixed or Other	10 (18)	10 (40)	10 (16)	
Married or partnered (% yes)	68 (120)	68 (291)	64 (99)	$\chi^2 = 0.7$; p = 0.658
Lives alone (% yes)	19 (34)	19 (83)	20 (31)	$\chi^2 = 0.1$; p = 0.978
Child care responsibilities (% yes)	33 (57)	21 (88)	20 (31)	$\chi^2 = 10.5$; p = 0.005 1 > 2 and 3
Care of adult responsibilities (% yes)	7 (12)	8 (31)	11 (16)	$\chi^2 = 1.8$; p = 0.408
Currently employed (% yes)	40 (71)	36 (153)	28 (43)	$\chi^2 = 5.6$; p = 0.062
Income*				
< \$30,000+	17 (28)	16 (63)	17 (23)	KW, p = 0.019; 1 > 3
\$30,000 to <\$70,000	14 (22)	20 (78)	32 (44)	
\$70,000 to < \$100,000	16 (25)	15 (59)	16 (22)	
≥ \$100,000	53 (86)	49 (191)	36 (50)	
Cancer diagnosis				
Breast	48 (86)	39 (167)	31 (48)	$\chi^2 = 16.4$ p = 0.012**
Gastrointestinal	27 (48)	29 (123)	35 (55)	
Gynecological	18 (32)	19 (81)	17 (27)	
Lung	7 (12)	14 (60)	17 (26)	
Type of prior cancer treatment				
No prior treatment	14.1 (25)	21.5 (91)	25.7 (39)	$\chi^2 = 8.3$; p = 0.219
Only surgery, CTX, or RT	49.2 (87)	43.3 (183)	40.8 (62)	
Surgery & CTX, or Surgery & RT, or CTX & RT	20.9 (37)	21.7 (92)	18.4 (28)	
Surgery & CTX & RT	15.8 (28)	13.5 (57)	15.1 (23)	

* For post hoc comparisons for Income, the “>\$100,000” group served as the referent group.

** Compared to patients with GI or lung cancer, patients with breast cancer were more likely to prefer an active role

Abbreviations: CTX = chemotherapy, RT = radiation therapy, SCQ = Self-Administered Comorbidity Questionnaire, SD = standard deviation, KW = Kruskal-Wallis

Table 2. Physical and Psychological Symptoms by Decision-Making Role among Patients with Concordant Roles (n = 765).

Characteristic	Active (1) n = 178 23.3%	Collaborative (2) n = 431 56.3%	Passive (3) n = 156 20.3%	Statistics
	Mean (SD)	Mean (SD)	Mean (SD)	
Center for Epidemiologic Studies-Depression Scale	12.6 (9.8)	12.5 (9.4)	12.4 (9.4)	F = 0.02; p = 0.980
Spielberger State-Trait Anxiety Inventories				
State anxiety	33.8 (13.3)	33.4 (12.0)	33.1 (12.5)	F = 0.09; p = 0.907
Trait anxiety	34.6 (11.0)	34.9 (10.6)	34.6 (10.2)	F = 0.15; p = 0.861
	% (N)	% (N)	% (N)	
Any pain				
No	35.4 (63)	25.3 (109)	29.4 (45)	$\chi^2 = 6.31$; p = 0.043 1 < 2
Yes	64.6 (115)	74.7 (321)	70.6 (108)	

Table 3. Psychosocial Adjustment Characteristics by Decision-Making Role among Patients with Concordant Roles (n = 765).

Characteristic	Active (1) n = 178 23.3%	Collaborative (2) n = 431 56.3%	Passive (3) n = 156 20.3%	Statistics
	Mean (SD)	Mean (SD)	Mean (SD)	
Connor-Davidson Resilience Scale	30.3 (6.2)	30.4 (6.3)	28.8 (6.4)	F = 3.8; p = 0.022; 2 > 3
Brief COPE				
Active coping	4.1 (1.6)	4.0 (1.6)	3.5 (1.8)	F = 8.7; p < 0.001; 1 and 2 > 3
Planning coping	3.4 (1.8)	3.4 (1.7)	2.7 (1.9)	F = 8.9; p < 0.001; 1 and 2 > 3
Positive reframing	3.4 (1.9)	3.5 (1.9)	2.8 (1.9)	F = 8.3; p < 0.001; 1 and 2 > 3
Acceptance	4.6 (1.3)	4.7 (1.3)	4.6 (1.4)	F = 1.1; p = 0.339
Humor	2.8 (1.9)	2.3 (2.0)	1.9 (2.0)	F = 8.4; p < 0.001; 1 and 2 > 3
Religion	2.6 (2.3)	3.0 (2.3)	3.0 (2.2)	F = 2.1; p = 0.122
Emotional support	4.3 (1.5)	4.5 (1.6)	3.9 (1.9)	F = 7.2; p = 0.001; 2 > 3
Instrumental support	3.2 (1.8)	3.5 (1.7)	2.9 (1.9)	F = 5.5; p = 0.004; 2 > 3
Self-distraction	3.5 (1.6)	3.4 (1.7)	3.4 (1.9)	F = 0.5; p = 0.608
Denial	0.5 (1.1)	0.5 (1.1)	0.4 (1.0)	F = 0.9; p = 0.337
Venting	2.0 (1.6)	2.0 (1.6)	1.6 (1.5)	F = 2.7; p = 0.068
Substance use	0.2 (0.5)	0.2 (0.7)	0.2 (0.9)	F = 0.5; p = 0.629
Behavioral disengagement	0.2 (0.6)	0.2 (0.7)	0.2 (0.6)	F = 0.4; p = 0.667
Self-blame	0.9 (1.3)	0.8 (1.2)	0.8 (1.2)	F = 0.2; p = 0.819
Mental Adjustment to Cancer				
Fighting spirit	51 (5.7)	52.1 (5.7)	51.4 (5.5)	F = 2.3; p = 0.104
Anxious preoccupation	23 (4.2)	23.5 (3.5)	22.8 (2.3)	F = 2.6; p = 0.074
Helplessness/hopelessness	8.6 (3.0)	8.9 (2.9)	9.2 (2.9)	F = 1.6; p = 0.211
Fatalism	16.2 (3.2)	17.3 (3.1)	18.7 (3.4)	F = 24.2; p < 0.001; 1 < 2 < 3
Avoidance	1.5 (0.7)	1.5 (0.8)	1.5 (0.8)	F = 0.3; p = 0.736
Positive adjustment	52.9 (6.2)	54.6 (6.2)	54.2 (6.0)	F = 4.2; p = 0.015; 1 < 2
Negative adjustment	28.9 (7.5)	30.1 (7.1)	30.4 (7.3)	F = 2.0; p = 0.136
NEO-Five Factor Inventory				
Neuroticism	42 (11.2)	42.2 (10.4)	44.0 (10.0)	F = 1.6; p = 0.201
Extraversion	53.0 (11.0)	53.5 (11.2)	52.3 (11.5)	F = 0.6; p = 0.552
Openness	57.1 (11.6)	55.3 (11.2)	53.0 (10.6)	F = 5.4; p = 0.005; 1 > 3
Agreeableness	54.7 (10.4)	55.7 (11.8)	55.3 (10.9)	F = 0.5; p = 0.630
Conscientiousness	51.5 (9.8)	50.9 (10.2)	50.4 (10.9)	F = 0.4; p = 0.655
Impact of Event Scale-Revised				
Avoidance	0.8 (0.6)	0.9 (0.7)	1.0 (0.7)	F = 1.6; p = 0.194
Intrusion	0.9 (0.8)	0.9 (0.7)	0.9 (0.8)	F = 0.01; p = 0.999
Hyperarousal	0.6 (0.6)	0.6 (0.6)	0.6 (0.6)	F = 0.3; p = 0.783
Mean of 3 subscales	2.4 (1.8)	2.5 (1.7)	2.5 (1.8)	F = 0.3; p = 0.773
Total	17.5 (13.3)	19.5 (12.6)	18.3 (13.3)	F = 0.4; p = 0.704