Special Article

Prospective Integration of Cultural Consideration in Biomedical Research for Patients with Advanced Cancer: Recommendations from an International Conference on Malignant Bowel Obstruction in Palliative Care

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Abstract
In the setting of an international conference on malignant bowel obstruction as a model for randomized controlled trials (RCTs) in palliative care, we discuss the importance of incorporating prospective cultural considerations into research design. The approach commonly used in biomedical research has traditionally valued the RCT as the ultimate "way of knowing" about how to best treat a medical condition. The foremost limitation of this approach is the lack of recognition of the impact of cultural viewpoints on research outcomes. We propose that interest relevant to cultural viewpoints should be emphasized in

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conceptualizing and interpreting research questions, designs, and results. In addition to recognizing our cultural biases as individuals and researchers, we recommend two major shifts in designing and implementing RCTs: 1) inclusion of a multidisciplinary team of researchers to inform the diversity of perspectives and expertise brought to the research, and 2) use of mixed methods of inquiry, reflecting both deductive and inductive modes of inference.   J Pain Symptom Manage 2007;34:S28–S39. © 2007 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Introduction

The end-of-life period is multidimensional and culture dependent, presenting a challenge to those conducting research among and for patients with advanced cancer. Confronting terminal illness is stressful for patients, families, and professional caregivers. For patients with incurable illnesses, the goals of care may shift from aims for "cure" to alleviation of suffering, support for the best quality of life until death occurs, and provision of comfort at the end of life.[1,2] With such goals in mind, the charge to those conducting research in palliative care is to identify optimal approaches that alleviate suffering and provide comfort. Large gaps of knowledge persist in the published research that addresses end-of-life care. However, conducting research among patients and families who are in the end-of-life phase of cancer survivorship is methodologically challenging, especially due to psychosocial-spiritual elements at end of life. The cultural dimensions of the patient, family, health care team, and researcher assume key importance at virtually all phases of this research process. While all research, not only end-of-life research, intersects with the cultural dimension, addressing it is especially important in end-of-life care, where culture shapes the attitudes and behavior of patients, families, and researchers toward death and dying.

The Malignant Bowel Obstruction (MBO) Conference provided a forum for multidisciplinary participants to develop and disseminate research methodologies well suited for examining this end of the cancer survivorship trajectory. MBO was selected as a "model" for research examining palliative care because it is a common clinical problem with a plethora of treatment options, and little prospective research. Thus, the charge of the group was to examine and develop approaches to conducting research that would not only address the state-of-the-art treatment of MBO, but also provide ways to approach research on other end-of-life questions. Within this context, one of the key topics discussed was *culture*, especially as it pertains to this vulnerable population, and the manner with which it interacts with other variables, thereby pointing to the need for rigorous research designs. We present the discussion of the subgroup whose charge was to focus on the issues of culture when conducting research with this population.

The culture subgroup was composed of a multidisciplinary group of health care professionals involved in research on cancer care problems. The members of this group represented medicine, nursing, social work, sociology, anthropology, spiritual care, and public health, all of whom had been involved with research addressing cultural issues. The group focused on several key areas: definitions of culture, cultural implications of the randomized controlled trial (RCT) approach to research, alternative research methodologies, application of cultural sensitivity to the various steps in the research process, and recommendations for a culturally sensitive research approach.

Background

Culture is defined in numerous ways across and within disciplines such as anthropology, sociology, and health research. We offer two definitions to inform our discussion of the

intersection of culture and research. The United States Department of Health and Human Services Office of Minority Health defines culture as "integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values and institutions of racial, ethnic, religious, or social groups."[3] Culture enables its members to adapt to changing ecologic environments to assure their survival and well-being. Cultures provide the meaning of life and proscriptions of behavior to achieve that meaning.[4] As reflected in these definitions, culture is multidimensional and dynamic. It guides worldviews and group, as well as individual, decision making[5] and strongly influences how people understand and make meaning of illness, treatment, and death.

Several challenges occur in the incorporation of cultural perspectives and variables in research. First, the concepts of race and ethnicity may be erroneously applied interchangeably. From the viewpoint of the anthropologist and the sociologist, ethnicity is the more relevant term. Race is a construct based on the mistaken historical notion that there are subspecies in the human species that have phenotypic similarities, an incorrect notion clarified by the presence of more intragroup than between-group genetic variation.[6,7] By contrast, ethnicity refers to one's identity with a subculture group in a multicultural society, a relation to a collective identity, which is influenced by acculturation and assimilation. Both concepts, race and ethnicity, are used as separate, required research categories by the National Institutes of Health in their policy for the Inclusion of Women and Minorities as Subjects in Clinical Research.[8] The purpose of this policy is to monitor research proposals for the inclusion of women and members of minority groups and their subpopulations. The categories created for these concepts were created as social political constructs not scientific categories and may be used in research to report outcome differences across groups. The 1997 Federal Government Office of Management and Budget Directive 15 defined the two ethnic categories addressing Hispanic populations as 1) Hispanic or Latino and 2) Not Hispanic or Latino.[9] The five racial categories are defined as American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White.[9]

The shortcoming of the application of these categories for the identification of minority participation in research is the lack of in-depth information on the culture of the participants in biomedical research. Quantitative research methodologies that use these categories are not designed to capture the multidimensional and dynamic nature of culture. It is worth noting that culture, ethnicity, and race are different concepts and should not be mistakenly considered synonymous with culture.[10]

In addition to ethnicity, an individual's culture identifies results from affiliation with numerous social and population subgroups, each with its own culture. Although most often associated with ethnicity, culture also reflects associations such as religion, nationality, rural/urban setting, sexual orientation, immigrant status, geographic region, and socioeconomic status. Even these sources of culture, when measured in health research, may be presented as *discrete categories* and not capture the richness of the individual's cultural influences and identity. Today's reality of globalization and intermingling of people from varied backgrounds demonstrates to us the key role of culture. Clearly, ethnic affiliation and experience of culture are complex, multifaceted and dynamic, and difficult to describe via discrete categories. Expressions of culture are influenced not only by cultural origins but also by acculturation and assimilation. Unfortunately, even measures of acculturation that attempt to capture multiple dimensions have been used summarily as single variables, reducing the impact of their efforts to capture concepts of culture.[11,12] The significance of the limitations noted above is the inability to conceptualize and operationalize the culture of the individuals who participate in research, and points to the need for other research approaches.

An important consideration in conducting research is the reality that both researchers and research subjects have cultural perspectives and dimensions. Whether affiliated with the majority or minority culture of a society, all people come from unique cultural backgrounds. Since the majority culture tends to be the standard of comparison for understanding how minority cultures are different, people

often overlook the fact that the majority culture is, nonetheless, a culture, too. It is not a blank or neutral state. Therefore, care should be taken to acknowledge and explore the culture of the researchers and the research participants.

Biomedical research is itself a social product, shaped by social, cultural, and political factors.[13] In the United States, medical and health practice and research reflects attitudes and viewpoints of European American culture,[14] as well as the various health research disciplines, and the institutions at which the research is conducted. For example, Western Euro-American culture's focus on individuality and autonomy contrasts to many world cultures that focus on the social collective and interconnectedness.[4,15] Furthermore, researchers aim to be objective and unbiased, hoping not to influence the outcome of the research and hoping to uncover generalistic and universal truths. However, the research training of disciplines involved in research is a powerful influence on the design and interpretation of research. The perspective of the researcher is shaped not only by personal cultural components such as ethnicity, religion, and gender, but also by broader cultural backgrounds such as the researcher's profession and discipline, specialty, and institutional setting. He or she brings culture to the research by the very way in which the problem is conceptualized, the questions are asked, and the responses are understood. This points to the value of a multidisciplinary team approach to research, wherein different viewpoints, dependent upon the individual's culture, can add to the richness of the research being conducted.

Palliative care practice has long recognized the importance of culture. Variations in the experience and meaning of symptoms, such as pain, are known to exist within and across cultural groups.[13,16−18] Perhaps even more apparent and recognized is the tremendous diversity in perspectives and traditions around the process of dying and end of life.[19−23] In addition to culture, common concepts of palliative care include the family as the unit of care, and the need to involve many disciplines in providing care (e.g., medical, nursing, social workers, psychologists, chaplains). Thus, great potential exists for cultural differences among palliative care patients, families, and practitioners, further demonstrating the need to explore various designs for palliative care research, and to recognize the value of a multidisciplinary research team.

Prospective Cultural Consideration

For culture to enrich medical research, it needs to be integrated into the planning of the research design. One way to achieve this is the mixed method approach, wherein both inductive and deductive approaches to research design are developed. Mixed methods are increasingly being used in research on the areas of health and culture.[24−26] The qualitative approach can be thus incorporated to capture the richness of the cultural variations among research participants, and will likely include such approaches as open-ended questions, interviews, and focus groups. Specific aims of the overall research proposal should address the cultural perspective and reflect those aspects of the research that will be qualitative.

The call for expanding methods of inquiry to more effectively capture cultural variations grows from the tendency of biomedical culture to remove context. The deductive approach primarily used in biomedical research uses a theory-driven approach that favors discrete, close-ended questions to measure variables hypothesized to influence the ultimate topic of inquiry. Researchers may reduce situations to their most "essential" questions to focus on answering the ultimate question of the study. This reductionistic approach has practical considerations, such as simplifying data collection and requiring less time and burden on research subjects and staff. Furthermore, batteries of close-ended questions that explore complex aspects of people's experiences provide a simple and quantifiable format of answers that can be efficiently collected from large samples of study participants. Although much valuable information is gathered through these methods of inquiry, they are inherently limited in the degree of depth and individual variation they can capture. Consequently, it becomes crucial to also use research methods to capture cultural variations in participants' ways of understanding

and viewing the research topic and research questions.

For example, distinguishing between disease and illness clarifies the importance of including prospective cultural consideration in designing medical research. Physicians and other health care providers often deal with the disease, the change in the biological state. Illness, however, is the human experience of symptoms, including the perception, adaptation, and response to those symptoms.[27,28] Each individual's experience of illness is somewhat unique, even in the setting of identical disease. The usual perspective of the physician is that of disease, by nature of the training for medicine. Other members of the multidisciplinary research team may broaden this perspective to that of illness. These members may include social workers, nurses, spiritual care providers, and psychologists. Thus, the multidisciplinary research team can augment deductive research by promoting inductive qualitative methods that capture multidimensionality and illuminate cultural and individual variations.[29]

Applying Prospective Cultural Consideration to Research on MBO

Integrating attention to the influence of culture into an RCT on MBO might begin with an expansion of the subject. To begin, the consideration of MBO as both a disease and an illness will broaden the view to both that of the physical condition as well as the personal experience and meaning of that physical condition. When considered an illness, cultural perspectives become apparent. Illness does not respond to a biomedical/biophysical model of treatment; illness responds to a biopsychosocial-spiritual model of care based within individual meaning and his or her cultural group's interpretation of the condition.

A multidisciplinary approach to the research will enrich both the research team and the methods used to answer the research questions. The presence of different disciplinary perspectives in the research design process will allow for varied approaches to the different dimensions of the research and considerations in the different phases. Combining clinical researchers and applied scientists creates a diverse research team with numerous disciplinary cultures that may include physicians, nurses, social workers, clergy, anthropologists, sociologists, psychologists, and statisticians. The varied perspectives and expertise of the different disciplines will help to create a research design that is more able to capture the "different ways of knowing and understanding" across individuals and cultures of both the patients and the research team members. Each phase of research must be cognizant of the cultural components. Each of the following steps in research provides opportunities for integrating methods that will capture cultural perspectives: formulation of the research question, recruitment, informed consent, methods, interpretation of responses, and reporting of results. Throughout each step of research, attention to the cultural component is accomplished through careful communication with the patient, the family, and among the research team members.

Formulation of the Research Question

Cultural consideration recognizes the importance of what is asked and of the assumptions and biases in the very questions that are addressed. Formulating the research question requires an understanding that there are differences in how cultures construct reality and alternatives in ways of knowing. How we understand the world and know what we know is culturally bound. Conducting studies on MBO can provide a setting for seeing the influence and significance of such cultural variations. Treatment of MBO occurs in the context of palliative care, where comfort and quality of life are the primary concerns and death is expected. We already recognize there are tremendous variations in how cultures view and understand the process of dying and death. Implementing a study on the treatment approach to MBO designed by a multidisciplinary team and designed with mixed methodology provides an opportunity to explore patients' responses inclusive of their cultural perspectives in dialogue with those of the treatment team. For example, questions posed might address the decision-making process, including issues of truth telling and patient autonomy in decision making. Communication about the study question should include a description of the treatment options to determine

patients' and families' views and concerns about surgery vs. medicine vs. other treatment approaches, some of which may be driven by culturally-based perspectives.

Research questions that allow revealing of cultural issues can provide insight into the interpretation of the results of the study. Hypotheses about which treatments are effective for MBO may be culturally inclusive by addressing the possible impact of individual and cultural differences on the desired outcomes along the disease trajectory. In the instance of MBO, the role of food and eating in various cultures may be a critical element of how people evaluate information about potential treatment outcomes, and consequently, treatment options. Such an approach reflects the understanding that outcomes are socially contextualized rather than existing in a cultural vacuum. In the mixed method approach applied concurrently (i.e., use of quantitative and qualitative methods at the same time during the study), the qualitative research question can provide a true picture of each individual's MBO experience. Beginning with a broad focus, the research questions could be "How do patients with advanced cancer describe their illness when confronted with a malignant bowel obstruction?" and "How do patients with advanced cancer describe their illness during surgical or medical treatment of MBO?" Additional specific research questions that would invite culture-illuminating data could include 1) which side effects and possible outcomes do patients and families perceive will accompany each treatment choice, 2) what do these side effects and possible outcomes mean to individuals of different backgrounds, beliefs, and values, and 3) how might variations in these meanings affect people's assessment of effective and acceptable treatment?

Recruitment

An important consideration in recruiting research participants is recognizing that research itself is an artifact of a European culture, and foreign to most people not of this background or educational level. Furthermore, it is helpful to understand that the RCT is a Western Euro-American approach to finding answers to a question, and, therefore, may be potentially unfamiliar, confusing, and intimidating. Qualitative approaches that address research

questions on culture may use techniques that are unfamiliar such as audio-taped interviews, and/or participating in focus groups. These methods will require additional explanations. Recognizing these cultural elements can inform how researchers approach prospective research subjects, exploring people's understanding of the research approaches planned, and providing explanations as needed.

One aspect important in recruitment is to describe what role family members play in treatment decisions. This can be determined by asking the patient which family member(s), if any, should be approached by the researcher regarding treatment of the patient's condition and participation in a research study.

Another challenge arises surrounding the issue of including non-English-speaking participants in the research. This frequently means translating informed consent forms, as well as measures, and having available trained translators to assist with administration of the research. Translation itself must include not only lingual translation but also concept translation, a more difficult goal to achieve given that some Western concepts do not exist in the same way in other cultures and vice versa. Translation procedures require forward and backward translation, and pretesting the product with a sample of the population for semantic, metric, and conceptual equivalence.[30] Use of family members as translators, especially minors, should be avoided. These approaches may require additional resources for implementation. However, inclusion of non-English-speaking patients increases the generalizability of the study results.

A reality of biomedical research has been the difficulty of recruiting participants from minority ethnic populations. Inclusion of members from the minority populations in the research design team, using linguistically and culturally relevant materials, testing research materials through focus groups, and reaching out to minority populations through community meeting places (places of worship, community centers) are all positive steps toward recruiting members of ethnic minority communities.[31,32] Although such efforts do not guarantee a representative recruitment of the population, they are important steps toward building trusting relationships with communities and learning how elements of

the research need to be tailored for different groups and cultures.

Informed Consent

Informed consent documents, originated to protect the research participant, have expanded into legal documents that include extensive content on adverse effects, some of which are extremely rare. These documents have evolved to be used as much to protect the researchers from litigation as to ensure the informed consent of the participants. The emphasis on risk makes it difficult to invite people to participate in research. Most Institutional Review Boards that approve these documents scrutinize them for language thought comprehensible by non-medical people. Nonetheless, the legalistic language, foreign to most people who are not regularly involved in research, may be intimidating and confusing regardless of one's cultural background, and more so for non-Western, non-Euro-American patients who are unfamiliar with the contractual nature of informed consent and research in clinical encounters. Approaches to informed consent reflect the assumed (but unarticulated) Western perspective of individuality and autonomy as universally paramount in medical care and decision making. Recognition of the culturally-based nature of this perspective should include the Western centrality of the patient-centered approach to care, which may be contrasted to other cultures' family-centered approach.

The intent of the informed consent document as the basis for a discussion between prospective participant and researcher should be reemphasized. Here again, the priority is on clear communication with the patient and family. It is an opportunity for exploring the patient's interpretation of the information, allowing clarification of unfamiliar concepts, acknowledging of culturally-specific concepts in the research, and allowing trust to build between participant and researcher. In talking with the patients about the study and seeking informed consent, the researcher may open the communication about family issues by asking patients whether there is anyone besides the patient that the clinician or researcher should talk with before signing the consent form. It is important to avoid medical or complex jargon by checking for understanding of what has been presented, using statements such as "So I can make sure I'm explaining this well for you, please tell me what your understanding is about your illness and the treatment we're considering."[33] Such processes require a time investment on the part of both prospective participant and researcher, but the result may be rewarding because the patient and family will be truly willing and able to participate as a partner in the research process. A less considerate process may end with the prospective participant not participating or participating under conditions that unintentionally discourage future research participation.

Sampling

Determining the study sample is a basic component of research design that requires cultural consideration. In studying treatment options for MBO, the sample should include participants from all, or as many as possible, ethnic and cultural groups that may require treatment for this condition in the institutions or geographic spheres where the research is to be done. Such inclusion holds numerous challenges but should not be quickly dismissed because of them. The challenges were addressed in the discussion of recruitment. However, a sincere and concerted intention to include a diverse study sample must be in place to allow the possibility for the most culturally varied sample of research participants. Strong efforts to be inclusive in the planning stages of the research will allow outcomes to be more broadly generalizable and more effective for allowing examination of culturally-based differences.

Methods

Methods include information about the sample population, the design, and the measurement approaches. The design proposed for including the cultural context in the MBO clinical trial is a mixed method design where both quantitative and qualitative data are collected. Two general strategies are available in applying a mixed method approach: sequential procedures and concurrent procedures. Each of these is described in Table 1. Selection of the approach depends on the availability of the sample, and whether one

Table 1
Mixed Method Strategies

Sequential Approach
   The researcher seeks to elaborate or expand findings of one approach (quantitative) with another (qualitative). Either approach can begin the study wherein the quantitative approach provides for a larger sample leading to generalization to a larger population. Subsequently, the qualitative data provide in-depth information on a small part of the sample.

Concurrent Approach
   In this approach, the researcher collects qualitative and quantitative data at the same time and then integrates the information collected during the interpretation phase.

set of data will be needed before moving to the other set of data. For example, an RCT of MBO using a sequential approach to the design may be operationalized by first using broad quantitative questionnaires to gather patients' responses to the treatment and then subsequently selecting a small group of the population for in-depth interviews. In a concurrent study, both quantitative questionnaires and open-ended questions or interviews would be carried out at the same time.[34] Examples of each of these approaches for an RCT with MBO are found in Table 2. Examples of other research that has used mixed methods are provided in Table 3.

Designing research measures highlights the importance of what is asked and how it is asked. Multidisciplinary approaches to the research are extremely valuable in this component of the design process as they enrich the methods by which to arrive at study conclusions. As noted in the section on formulation of the research question, the seemingly straight-forward biomedical question of which treatment is better for MBO needs to be understood in greater complexity. How do we better document what is going on for research participants? What dimensions of the experience need to be included in the measures? How do we measure different individuals' and cultures' ways of knowing and understanding the situation?

It is here that the deductive approach of RCTs may be greatly influenced to include cultural variations. Application of a mixed method approach, one that uses both deductive and inductive research methods, will enrich the research results. Mixed methods have long been used in social science research. A fundamental difference in the methods makes their combination especially powerful. Deductive methods, most often quantitative, test predetermined questions and hypotheses. In MBO research, deductive reasoning would lead to a hypothesis such as "Treatment A will be more effective than Treatment B," for which measures such as blood loss and postoperative eating capacity may be used to gather data. In contrast, inductive methods, usually qualitative, ask questions from which conclusions are made and theory is built. The inductive approach allows for gathering data that will build knowledge and understanding about how cultural issues and perspectives relate to MBO treatment choices, illuminating topics and variables for future research about which researchers may not have known to ask. Such methods, when applied to MBO research, would include administration of interview questions such as "What life-style priorities do you [the patient] have that may influence which treatment you would prefer?;" "Given the following possible risks and benefits of two treatments for MBO, how would you decide which treatment may be better for you?;" "What symptoms have you been experiencing and how have these affected your daily life?;" and "How has your quality of life

Table 2
Mixed Method Examples for an RCT on MBO

Sequential
   Collect information on quality-of-life responses of all patients. Select the top and bottom quartiles of the quality-of-life measures and interview a small sample (5−8 people) from each with a semistructured questionnaire.

Concurrent
   Administer questionnaires that include both quantitative data (deductive) and open-ended interview (inductive) questions. Collect data at the same time.

Table 3
Sample Applications of Mixed Methods in Health Research

Title of the Paper	Methods Used	Mixed Method Approach
Thrombolysis for acute ischaemic stroke: consumer involvement in design of new randomised controlled trial[35]	Completion of a quantitative questionnaire followed by focus group meetings	Sequential
Health-related quality of life in persons with long-term pain after a stroke[36]	Qualitative interview in conjunction with two quantitative self-report standardized questionnaires	Concurrent
Needs assessment and palliative care: the views of providers[37]	A mailed survey to hospices and palliative care inpatient units. A small number of sites were chosen for case study via interviews with senior staff	Sequential
Qualitative and quantitative evaluation of a new regimen for malignant wounds in women with advanced breast cancer[38]	Qualitative interviews of patients in conjunction with quantitative evaluation of the condition of the wounds	Concurrent

changed since having this disease?" An important component of this approach is to ask participants what concepts are or are not relevant to them. It should be noted that although quantitative and qualitative methods often reflect the two reasoning approaches, qualitative methods may be used both deductively and inductively. That is, open-ended questions may be used to ask questions aimed at testing a hypothesis (deductive) or illuminating information that will serve to build theory (inductive). The key distinction is between the deductive and inductive approaches to inquiry. The combination of the approaches allows both testing and building of theory, informing current questions and building new information about which questions could not have even been imagined without including the insights and perspectives of the individuals affected.

Interpretation of Responses

Although biomedical research often views itself as objective science, no research is free of subjectivity as long as human beings are involved in its design, implementation, and interpretation of results. Thus, interpreting results requires judgment and application of ways of understanding. How data are analyzed and represented reflects a cultural position of how information is understood. Consequently, recognizing that there are always biases in the interpretation of responses and results is an important component of considering culture in research. We cannot assume that all cultures view the same results of a situation as "good" or "bad" in the same way. For example, different cultures may have dramatically different interpretations on the definition, meaning, and value of suffering. Interpretation of results needs to include recognition that the research team's interpretation does not necessarily reflect a universal understanding of the research data. Providing alternative interpretations based on available data, literature, or contributions from the multidisciplinary research team will enrich the application of results by identifying and including the larger universe of potential responses.

Reporting of Results

Reporting of results should attend to several cultural elements. First, results need to be carefully presented so they acknowledge cultural biases of research. Second, presentation should honor the cultures of those in the research, noting the diversity and reflecting respect for that diversity. Third, limitations should be addressed in the report, especially as it relates to the potential intragroup variations within the population that participated in the research. Finally, results should be reported in a way that is relevant not only to the research world but also to the clinical world and to the research participants. This may necessitate publishing in scientific, practice-oriented journals of multiple disciplines and lay journals, and magazines. Scientific reporting of the research is clearly important, but equally important is reporting of the research findings in such language and method that those who participated can understand what was learned and how it is being

understood. Such cultural consideration acknowledges that research has a culture of its own, one that is generally foreign and of limited immediate benefit to the patients who participate in it.

In addition to reporting results in publications, conference and meeting presentations can be used to disseminate research results. Professional conferences across disciplines, specialties, researchers, and practitioners vary greatly, providing a broad range of target audiences to which results can and should be culturally tailored. Patient and advocacy oriented meetings on cancer and end-of-life care, in addition to smaller community-based speaking venues, offer excellent opportunities for conveying information to the lay public, including participants in the research. Such speaking engagements call for specific attention to use of nonjargon language and the acknowledgment of the cultural perspectives that affected design, implementation, and outcomes of the research.

Recommendation: Integrating Culture into Research for Patients with Advanced Cancer

The culture of biomedical research has traditionally valued the RCT as the ultimate "way of knowing" about how to best treat a medical condition. This approach defines the research problem in biomedical terms of disease and pathology and assumes a specific set of outcomes as signifying "good" or "bad" results of treatment. The cultural limitations of this perspective primarily and initially appear in the lack of recognition that this is, in fact, a specific cultural viewpoint rather than a universal way of asking, understanding, and interpreting a situation. Medicine and medical research tend to decontextualize. Unless we make a concerted effort to frame and do the research with the cultural context in mind, we will not accurately or effectively advance our understanding. Acknowledging the cultural perspective we use allows us to expand our research approach to capture other ways of knowing and understanding that will provide a much better reflection of reality than one culture's viewpoint could ever allow.

We recommend two major shifts that will assist researchers in integrating prospective cultural consideration into their work. The first is ensuring a multidisciplinary team of researchers for the study. The variety of disciplines involved in the designing of research can participate in developing, implementing, and interpreting all phases of the research, and reflect different ways of seeing, approaching, and understanding a research situation. The collaboration among disciplines requires clear and open communication. The second major shift that is needed is a move toward using mixed methods of research. The use of both deductive and inductive methods of inquiry and measurement will result in a much richer and more complex understanding of the research topic. It will allow for the diversity of individuals' and cultures' ways of knowing and understanding to be heard and integrated into the researchers' understanding of the research topic. These approaches challenge us as researchers to recognize our own cultural positions, both personal and professional, and to work beyond familiar methods of inquiry and understanding to learn what people of different backgrounds, values, traditions, and beliefs experience. Without such efforts, our research boasts a universal truth that only reflects the limitations and narrowness of our vision, excluding and alienating the realities of many in our community and our world. Since it is unlikely that we intentionally or knowingly aim to these ends, we must make substantial efforts to integrate prospective cultural consideration into our research.

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