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IDENTITY AS A FRAMEWORK FOR METAPHOR USE IN CANCER MESSAGES

DESIGNED FOR RURAL, LOW-INCOME, OLDER ADULT WOMEN

A Thesis in

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by

Janice Raup-Krieger

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The thesis of Janice L. Raup-Krieger has been reviewed and approved* by the following:

Jon F. Nussbaum
Professor of Communication Arts and Sciences and Human Development and Family Studies
Thesis Co-Adviser
Co-Chair of Committee

Roxanne L. Parrott
Professor of Communication Arts and Sciences and Health Policy and Administration
Thesis Co-Adviser
Co-Chair of Committee

Michael L. Hecht
Liberal Arts Research Professor of Communication Arts and Sciences

Collins O. Airhihenbuwa
Professor of Biobehavioral Health

S. Shyam Sundar
Associate Professor of Communications

Eugene J. Lengerich
Associate Professor of Health Evaluation Sciences

James P. Dillard
Professor of Communication Arts and Sciences
Head of the Department of Communication Arts and Sciences

*Signatures are on file in the Graduate School.

ABSTRACT

Health communicators are often charged with the difficult task of communicating complex medical or scientific information to lay audiences. In the case of Phase III cancer clinical trials, communication efforts must help audiences understand both the medical and scientific aspects of treatment. Previous research has found that aversion to the scientific component, specifically randomization to a treatment condition, is a primary reason why individuals choose not to enroll in clinical trials. As a result, healthcare providers often use metaphorical language as a linguistic strategy to increase understanding and hopefully acceptance of randomization to treatment among patients. However, the effectiveness of this message strategy to produce outcomes favorable to clinical trial enrollment is unknown. Guided by McGuire's (1972) model of information processing, this study examined outcomes associated with randomization messages including attention, comprehension, yielding, arousal, and behavioral intention among a medically underserved audience of rural, low-income, older adult women. Formative research conducted with the intended audience led to the development of stimulus videos about randomization. A four-message condition between subjects pretest-posttest laboratory study was used to empirically test the effectiveness of these messages. Culturally tailored metaphor messages were compared to a conventional metaphor, a scientific definition, or attention control on outcomes specified in McGuire's model for information processing. No main effects for message strategy were found, however, message strategy significantly interacted with attention to predict posttest behavioral intentions. Implications of these findings for rural health message design are discussed.

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Chapter One

REVIEW OF LITERATURE

Introduction

Health inequities pervade the United States, resulting in some Americans having less access to and receiving a lower quality of healthcare than others (Smedley, Stith, & Nelson, 2003). The ethical principle of social justice maintains that inequities in health, which are systematic differences in health among social groups resulting from the relative social advantage or disadvantage, are inherently unfair (Braveman & Gruskin, 2003). Medically underserved groups bearing the brunt of health inequalities, also called health disparities¹, include racial and ethnic minorities, the uninsured/underinsured and the unemployed, people with low levels of education and/or socioeconomic status, and rural and inner-city populations (Haynes & Smedley, 1999). Health disparities derive from communicative practices that consciously or unconsciously reflect group stereotypes and prejudicial attitudes (Hecht, 1998). The strategic design of health messages is one strategy for potentially reducing both the existence and effects of these disparities (Maibach & Parrott, 1995).

In 1998, President William Clinton committed the United States to eliminating health disparities in six priority areas, including cancer screening and management, infant mortality, diabetes, heart disease, AIDS, and immunization by the year 2010 (Woolley &

¹ Brakeman and Gruskin (2003) argue that health inequities and health disparities should not be used synonymously because not all disparities in health are unjust. Certain health outcomes, such as female newborns generally having a lower birth weight than male newborns, are not health inequities because they cannot be argued to be unfair. However, the two terms will be used interchangeably herein because the initiatives described use the term health disparities and because its usage is congruent with the definition provided for social inequities in health.

Peters, n.d.). The elimination of health disparities subsequently became one of two overarching goals of Healthy People 2010, the United States' primary health promotion and disease prevention initiative (U.S. Department of Health and Human Services, 2000).

Health disparities are a form of social discrimination resulting from the enactment of prejudice (Marsiglia & Hecht, 1998; Ndiaye, Krieger, Warren, & Hecht, under review). Prejudicial attitudes are reinforced by social stereotypes, and communicated through both verbal and nonverbal messages (Hecht, 1998). The enactment of prejudice can be overt and obvious, as in cases of hate speech (Asante, 1998). It can also be subtle and manifest in socially accepted behaviors, as in the case of ageism. Ageism, which refers to enacted prejudice against elders, manifests in everyday speech and provides an excellent example of how social discrimination creates and reinforces health inequities (Nussbaum, Pitts, Huber, Krieger, & Ohs, 2005). A common enactment of ageism is the use of patronizing speech with older adults. A number of studies have demonstrated that physicians communicate differently with older patients than they do with younger patients, including being less respectful, providing less detailed information, and asking fewer open-ended questions (Adler, McGraw, & McKinlay, 1998; Beisecker, Helmig, Graham, & Moore, 1994; Street, 1991). Another difference is the utilization of patronizing speech (also referred to as "secondary baby talk"), which is often marked by an exaggerated tone, a slow rate of speaking, and simplified content (Hummert & Mazloff, 2001; Ryan, Giles, Barolucci, & Henwood, 1986). These manifestations of prejudice are likely to perpetuate health disparities between the young and aged.

If communication plays a role in causing inequities in health, communication must also play a role in potential interventions (Hecht & Baldwin, 1998). However, the ability of communication interventions to reduce health disparities is limited by the degree to which they place culture at the center of both theory and practice (Airhihenbuwa, 1995). Examples of this include Eurocentric health promotion and disease prevention programs in Africa that privilege visual forms of communication in African societies who rely on oral tradition as a primary means of cultural production (Airhihenbuwa, 1995). Thus, the effectiveness of a range of communicative efforts are often compromised because messages neglect the cultural, social, psychological, environmental, and historical factors that influence the health of the population (Freimuth & Quinn, 2004). As Airhenbuwa (1995) describes below, the cultural appropriateness of health communication efforts are intricately tied to program outcomes:

Thus the degree to which new programs are adopted is dependent on the extent to which they are culturally appropriate. Program planners and implementers should ensure that the method of health communication is in accord with the cultural reality consistent with the society's pattern of knowledge acquisition. In order for this to occur, the health promoters must understand, learn, and develop the skills they will need to reflect appropriately the cultural values of the target population (Airhihenbuwa, 1995, p. 122).

One common strategy for communicating about health is the use of metaphors. A metaphor is an implied comparison between two dissimilar entities, with the result that

the qualities of one are transferred to the other (Sopory & Dillard, 2002a). Metaphors are often perceived to possess extraordinary power to convey complex health or scientific concepts, possibly even more effectively than definitional approaches (Freimuth, Linnan, & Potter, 2000; Kreuter & McClure, 2004; Sopory, 2005). It has even been suggested that the use of metaphor can improve the cultural sensitivity of health messages (Freimuth, et al., 2000; Kreuter & McClure, 2004).

Physicians frequently rely on metaphor to enhance communication with patients on a range of issues, including asthma, HIV/AIDS, and cancer (Arroliga, Newman, Longworth, & Stoller, 2002; Sontag, 1989). “War” is a dominant framework for the creation of metaphors about illness, and has been applied to a wide range of health issues ranging from cancer to AIDS to the use of recreational drugs (Sontag, 1989). To illustrate using the cancer context, cancerous tumors are often constructed as the “enemy”, physicians as “commanders”, patients as “combatants”, and medical therapies as “weapons” (Reisfield & Wilson, 2004). Nevertheless, the suitability of metaphorical messages for use with particular audiences is seldom evaluated. Lance Armstrong, a prominent American cancer survivor who won the Tour de France six times after undergoing treatment, provides anecdotal evidence of how the military metaphor was used by an oncologist he consulted early in his cancer experience:

“I’m going to kill you. Every day, I’m going to kill you, and then I’m going to bring you back to life. We’re going to hit you with chemo, and then hit you again, and hit you again. You’re not going to be able to walk.

We're practically going to have to teach you to talk again after we're done.”

–Anonymous Oncologist (Armstrong, 2000)

The importance of focusing on language in the cancer context stems from the vastness of the disease and the disproportionate burden it places on certain populations. Cancer is the second leading cause of death in the United States, and as such, improving methods of cancer detection and treatment are a national priority (Eberhardt, Ingram, Makuc, et al., 2001). A number of cancer health disparities that result in poorer health outcomes for medically underserved groups have been identified across the cancer continuum (Haynes & Smedley, 1999). One such cancer disparity is the low number of medically underserved populations (i.e., racial/ethnic minorities, elderly, low-income, rural) enrolled in clinical trials (Di Maio & Perrone, 2003).

Lack of diversity in clinical trial enrollment is problematic from an equity perspective for two reasons. First, clinical trials are considered to represent the best possible medical treatment. It is unethical for social groups with greater resources to have greater access to this type of treatment than groups with fewer resources. Second, a lack of adequate representation from groups designated as medically underserved undermines the ability of a trial to demonstrate that participants are representative of the population that will be receiving the new treatment (Di Maio & Perrone, 2003; Hall, 1999). When this happens, the study

yields medical knowledge whose results are limited to the scope of the population studied.

There are numerous reasons people in general, and medically underserved populations in particular, might not participate in clinical trials. First, financial considerations play a role in the likelihood an individual will participate in a clinical trial. Having health insurance that will cover the cost of a clinical trial and limited out of pocket costs for additional laboratory or radiological tests positively influence the likelihood of trial participation (Klabunde, Springer, Butler, White, & Atkins, 1999; Mansour, 1994). Second, previous research has identified a number of reasons physicians may choose not to refer a patient to a clinical trial, including time constraints, lack of training, concern about deterioration of the physician-patient relationship, and a lack of recognition and compensation (Ross, Grant, Counsell, Gillespie, Russell, & Prescott, 1999). Social stereotypes, conscious or otherwise, also play a role in who is referred to trials. Physicians are reluctant to enroll older patients in clinical trials, despite the absence of medical evidence indicating that older adults would garner less benefit from participation than younger adults (Yee, Pater, Pho, Zee, & Siu, 2003). Reasons patients choose not to participate in clinical trials include the additional physical and time demands of clinical trial, high levels of uncertainty, and aversion to being randomized (Fallowfield, Jenkins, Brennan, Sawtell, Moynihan, & Souhami, 1998; Jenkins & Fallowfield, 2000; Ross, et al., 1999; Valentino, Andrykowski, & Wood, 1999).

Although there are many aspects of clinical research studies that need further exploration, the current state of research suggests that effectively conveying the meaning

of randomization to patients remains a primary challenge (Curbow, Fogarty, Chill, & Scott, 2004; Fleissig, Jenkins, & Fallowfield, 2001; Jenkins & Fallowfield, 2000; Jenkins, Fallowfield, Souhami, & Sawtell, 1999; Kemeny, Peterson, Kornblith, Muss, Wheeler, Levine, et al., 2003; Llewellyn-Thomas, Thiel, Sem, & Woermke, 1995). However, it is unknown what makes an effective randomization message. Thus, the purpose of this study is to investigate culturally appropriate methods for explaining randomization to a medically underserved audience of rural, low-income, older adult women by achieving the following three aims: 1) explore regional identity as an audience segmentation construct for clinical trial messages; 2) empirically test the effectiveness of using metaphor to explain randomization; and 3) test whether McGuire's (1972) model of behavior change can predict intentions to participate in clinical trials.

Review of Literature

Intersections of Culture, Identity, and Health

Culture is an oft-cited reason for health disparities. However, what is meant by the term culture, and the exact nature of the relationship between culture and health disparities is often more elusive. A contributing factor to this confusion is the overwhelming number of unique definitions for culture across disciplines. The dialogue on issues of culture has recently been aided by the creation of a typology that identifies seven themes that cut across the various definitions of culture (Baldwin, Faulkner, Lindsley, & Hecht, 2006). The first theme encompasses definitions of culture as structure and patterns, including language, attitudes, values, behavior patterns, relational structures, and social organization (e.g., political, legal, religious). The second theme

includes definitions that focus on the functions of culture, which refers to what culture does for people. For example, culture can fulfill a need for a sense of belonging through the creation of group identity. The third theme is comprised of definitions of culture as a process. Central to these approaches is the idea that culture is a dynamic rather than static phenomenon that serves as the basis of collective identity (Hecht, Jackson, & Ribeau, 2003). Culture as sense making is a process approach.

A fourth theme is definitions of culture classified as focusing on product. Products can be both material and nonmaterial, ranging from clothing and food to art, music and ritual. The fifth theme encompasses definitions of culture as refinement, which ranges in meaning from differences between humans and other species to variation among humans with regard to moral or intellectual refinement. The sixth theme is culture as group membership. The composition of social group memberships can range from the very large, such as membership in a national or racial/ethnic group to members, to quite small, such as members of a particular speech community (Philipsen, 1992). The seventh and final theme is culture as power or ideology. These definitions highlight the economic and political processes that enable one group to dominate others.

These themes are not mutually exclusive, and health interventions may benefit from layering or combining perspectives. Most importantly, the role of culture in health interventions should be articulated and interrogated so that underlying values and justifications come to the fore (Guttman, 2000). Culture is typically used in the health promotion literature to refer to a set of beliefs, ideas, traits, and/or practices that the “dominant culture” perceives to be negatively related to health outcomes, and is thus

labeled *cultural barriers* (Airhihenbuwa, Makinwa, & Obregon, 2000). This type of approach is grounded in the values and ideology of the interventionist rather than intended audiences (Guttman, 2000). The tendency to position the intended audience as the locus of the problem, rather than placing blame the social, political, or economic forces that influence health outcomes, is common in the context of rural health. The following section will further explore the current socio-political, economic, and legal concerns that are influencing rural health.

The Rural Environment

In many countries, the trend toward urbanization is creating economic and health disparities between populations who live in cities compared to those who live in rural areas. The inequalities afflicting vulnerable rural populations are slowly beginning to be considered in public health (Behringer, 1994; Dixon & Welch, 2000; Ndiaye, Krieger, Warren, & Hecht, in progress). The importance of creating geographic distinctions such as “rural” and “urban” in health research is to identify and address the unique health care challenges that our nation’s residents face on a daily basis.

Rural Defined

The two common classification systems used in the United States to distinguish between urban and rural populations were created by the U.S. Bureau of the Census and the U.S. Office of Management and Budget (OMB) (Ricketts, Johnson-Webb, & Randolph, 1999). The Census Bureau designates counties as urban or rural based on population size and residential population density. As of June 2003, the OMB uses a classification system based on Core Based Statistical Areas (CBSAs), which include

metropolitan and micropolitan statistical areas. Metropolitan Statistical Areas have at least one urbanized area of 50,000 or more residents. Micropolitan Statistical Areas must have at least one urban cluster of 10,000 or more residents, but less than 50,000.

Counties not included within a CBSA is simply called “Areas Outside CBSAs”. In other words, rural is a default category representing anything that is not urban. Complicating matters are classification systems developed by individual states. For example, the Center for Rural Pennsylvania has classified each county in Pennsylvania as urban or rural based on population density. Because each national and state classification system yields somewhat different results, a county could be considered urban by one definition and rural by another definition. For example, the Center for Rural Pennsylvania has classified 48 of Pennsylvania’s 67 counties as rural (28% of the state population), while the new OMB definition recognizes 13 Pennsylvania counties as Areas Outside CBSAs (only 3% of the state population). Contradictory methods of geographical classification can create problems for health research. For example, one study of urban rural substance use found significant differences between rural and urban substance use using a state classification system, but not with using the Census Bureau classification (Spoth, Goldberg, Neppl, Trudeau, Ramisetty-Mikler, 2001). Problems such as these foster a general lack of confidence in the meaning of such classification systems because it is unclear what social dimensions each is (or should be) measuring.

Despite the myriad of statistical ways to classify the population, there remains an underlying question as to whether any type of urban-rural dichotomy is adequate to assess the diversity of rural communities (Spoth, 1997). Current research that use such

dichotomies may place too much emphasis on “rurality” as a political entity by defining rural spaces by their population density and proximity to urban areas and not enough emphasis on the larger cultural factors that shape attitudes and behaviors about health (Scheer, Borden, & Donnermeyer, 2000). It seems unreasonable to expect that rural culture would be confined by physical boundaries such as county or state borders. This may have been true half a century ago when rural communities were insulated from the larger societies and were able to maintain a high degree of self-sufficiency (Hobbs, 1995). Today, it seems less likely that socio-cultural boundaries of rural life would respect the confines of political and geographical assessments. One primary reason the boundaries have expanded is a result of the shifting economic basis of rural communities, including the tendency for healthcare and social services to be centralized in urban areas.

Rural Economics

In the *Jakarta Declaration on Leading Health Promotion into the 21st Century*, the World Health Organization (1997) declared that poverty is the greatest threat to global health. Poverty tends to be more pronounced in geographically isolated areas, with 75% of the poor worldwide considered to be “rural” (World Resources Institute, 2005). Poverty is pervasive in rural areas due to lack of jobs or jobs that may not pay a living wage. Just half a century ago, the small communities of the rural U.S. were able to maintain a high degree of self-sufficiency that insulated them somewhat from the larger society (Hobbs, 1995). For example, many people were employed in traditional occupations such as farming, fishing, forestry, and mining. These positions paid a living wage and could be found close to home. Now, massive changes to the economic basis of

rural communities have resulted in the widespread loss of traditional occupations. Although politicians may be quick to point out that rural job growth remains strong, it is important to note that a disproportionate number of these jobs require little skill and receive low wages (Barkley, 1995). Low wages have a direct influence on healthcare, with about a third of lower-income rural residents lacking health insurance (Eberhardt, et al., 2001).

According to the prevailing wisdom in U.S. culture, the poor economic conditions in rural areas are a result of inadequate levels of education (Pittman, McGinty, Gerstl-Pepin, 1999). Research does suggest that rural residents generally have lower rates of formal education (high school and college) than urban residents (for a review, see Kannapel & DeYoung, 1999). However, the causal relationship between the two has been questioned in rural areas. One study suggests that higher income results in increased educational attainment, not the reverse (Pittman, et al, 1999). Pittman and colleagues (1999) also argue that this relationship is less pronounced in rural communities, if it exists at all. Cultural values likely play a role in both educational and vocational choices. Rural youth place high value on remaining close to friends and family, while opportunities for higher education and high paying jobs are often located outside the rural community (Kannapel & DeYoung, 1999; Wilson, Henry, & Peterson, 1997).

Rural Health

The rural health environment is comprised of the healthcare system that cares for the rural population and the health policies that shape the quality and delivery of that care. One of the most common rural health problems identified in the literature is access

to quality healthcare (Glasgow, Wright Morton, & Johnson, 2004). Healthcare facilities and providers tend to be concentrated in urban areas. Twenty percent of the population of the U.S. lives in rural areas, yet only 11% of the nation's health care providers work in rural communities (Van Dis, 2002). These patterns render services less accessible to rural residents than urban residents (Pande & Yazbek, 2003; Rahman, 2006). The United States is included in countries reporting a shortage of healthcare providers in rural areas, with particularly few female and minority providers (Gamm, Castillo, & Pittman, 2003). Specialized care is also problematic in rural areas. For example, it is common for people with serious diseases in some parts of the U.S. to travel 250 miles round trip to see a specialist (Heckman, Somlai, Peters, Walker, Otto-Salaj, Galdabini, et al., 1998).

One of the unique features of the rural health environment is the comparatively older age of the population. The percentage of adults over the age of 65 is significantly greater in rural counties (18.8%) as compared to urban counties (11.9%) (Larson, Machlin, Nixon, & Zodet, 2004). Thus, the challenges inherent in rural healthcare may be compounded by problems known to influence the medical treatment of older adults in general (Nussbaum, et al., 2005). These problems include findings that physicians disregard symptoms perceived to be part of the aging process, provide older adults with less medical information than younger patients, and provide differential treatment in critical care units (Adler, et al., 1998; Beisecker, Helmig, Graham, & Moore, 1994; Grant, 1996; Rivlin, 1995; Street, 1991). Perhaps most troubling of all are reports that physicians do not give older adults an opportunity to discuss all of their health concerns during medical consultations (Rost & Frankel, 1993).

Health policies also play a key role in maintaining the health inequities between urban and rural populations. A well-known exemplar is the U.S. Balanced Budget Act of 1997, which provided the authority for Centers for Medicare and Medicaid Services to implement a prospective payment system (PPS). Hospital payments under the PPS are adjusted to reflect “geographic wage variations,” which effectively mean lower payments to rural healthcare providers and higher payments to urban healthcare providers for the same services. Rural scholars have argued that this policy has strained the ability of local hospitals to employ a sufficient number of qualified physicians, which in turn, limits resident’s access to medical care (Ricketts, 1999b). The Minnesota Medical Association even filed a lawsuit to persuade the court system to correct the unequal managed care reimbursement rates. The Minnesota District Court dismissed the suit, ruling the unequal payment rates “wrong” and an “injustice”, but not unconstitutional (Ricketts, 2002). One reason for the lack of action to correct discriminatory policies aimed at rural populations is the lack of recognition of their status as a social group.

Rural as Identity

The changes that have occurred in rural areas over the last 50 years, such as the local loss of jobs that pay a living wage and the increasing urbanization of health care services, have increased the need for rural residents to travel greater distances for employment or healthcare. Such changes have necessitated a shift in the locus of rural community in recent years from physical space to “social space” (Hobbs, 1995). This shift has spurred recognition of the importance of rural residence in shaping identities (Ching, 2001; Ching & Creed, 1997).

Rural Identity

Creed and Ching (1997) make the case that “rusticity” is at the core of rural identities. Rusticity refers to identities rooted in “country” ideals (as opposed to those that are considered postmodern or urbane/sophisticated), such as high regard for practical know-how and disdain for cultural sophistication. For example, practical skills such as how to fix a vehicle or how to gut a deer may have greater social value than more abstract knowledge related to academic pursuits, such as philosophy or fine arts. The intergroup tension between the rustic and the urbane is enacted at the societal level through the stereotypes that each group has of the other. People who live in rural areas are often socially stigmatized as being “peasants” or “hillbillies”, and their culture and lifestyle are socially devalued (Creed and Ching, 1997). Even scholars often fail to recognize rural spaces as having cultural capital. Instead, rural areas such as Appalachia are treated as case studies for culture of poverty theories (Duncan & Lamborghini, 1994; Rabow, Berkman, & Kessler, 1983). In this way, stereotypes based on regional location help maintain the interdependence that group identities require. Put another way, “each comes to know the self by knowing what the self is not” (Hecht, Jackson, & Ribeau, 2003, p.243).

Previous research has identified both positive and negative stereotypes in the general population about people who live in rural areas. Rural people are often described as friendly, relaxed, and self-sufficient, with strong religious and moral values (W.K. Kellogg Foundation, 2001). In contrast, other studies have identified less flattering stereotypes for people living in rural areas, including noncommunicative, uneducated,

lazy, incestuous, and preoccupied with folk remedies and traditional healers (Cavendar, 1996; Cavendar & Beck, 1995). Both positive and negative stereotypes of members of “other” groups can have harmful consequences, including discrimination, because they can lead to communication that is adapted to membership in a group, instead of individual characteristics (Hummert, 1994a; 1994b). For example, providing medical treatment to an older adult on the basis of stereotypes rather than individual characteristics can reduce the quality of the care they receive. This is most obvious in cases where negative stereotypes of older adults such as despondent (e.g., depressed, hopeless, afraid, and lonely) or severely impaired (e.g., slow-thinking, incompetent, feeble, and inarticulate) are salient. In such cases, the older adult is likely to be perceived as lacking the requisite mental or physical ability to participate in medical decision. Although positive stereotypes of group members may be less harmful than negative stereotypes, they do not represent the ideal for effective communication. For example, communicating with an older adult based on the John Wayne conservative stereotype (e.g., patriotic, religious, conservative, and proud) or the perfect grandparent stereotype (e.g., kind, loving, generous, wise) may foster an interaction that makes it difficult for the older adult to express feelings that may be contrary to that stereotype, such as fear of death or anger towards God for allowing suffering (Hummert, Garstka, & Shaner, 1997).

Regional stereotypes are not limited to those directed toward rural residents. Urban stereotypes comprise a common theme of popular culture outlets with alleged ties to rustic constituencies, with the most visible being country music. In country music, and hard country in particular, “the country” is a figurative space as much as it is a literal one

(Ching, 2001). The lyrics often focus on issues of class, positioning the music and its listeners outside of contemporary culture without the possibility of social mobility (Ching, 2001). The perceived social distance between the high (urban) culture and the low (rustic) culture is demonstrated through country music that reappropriate labels that are typically intended to derogate rural people (e.g., “red-neck”).

Appalachian Identity

Some scholars have suggested that rural identity can be even further localized (Ray, 1987; Smith & Bylund, 1983; Wilson, et al., 1997). Smith and Bylund (1983) argued that people living within the rural areas surrounding the Appalachian mountain range maintain an “Appalachian identity.” Their claim was based on the results of a survey that indicated that Appalachian residents feel less respected than other Americans. An ethnographic study of a rural Appalachian community resulted in Ray (1987) identifying what he termed “core values” of Appalachian identity. These values included a regard for personal privacy, a desire not to hurt others’ feelings, and a belief in egalitarianism. Although Ray (1987) argues that Appalachian identity is marked by an emphasis on personal privacy, Wilson and colleagues (1997) maintain that Appalachian culture places an emphasis on connection with others. Their longitudinal study of low-income Appalachian youth revealed that several predictors of life satisfaction in rural areas are related to perceived connectedness with others, including living in a small community and being married (Wilson, et al., 1997). Given the limited and conflicting research on Appalachian identity, the following research question is posed:

RQ1: What aspects of cultural identity are salient to rural Appalachian women?

Faith and religion are often a central part of the experience of illness in rural areas (Horton, 1984; Simpson & King, 1999). Communication about the physical and mental health of the local community has been found to be a vital part of rural religious services through the form of prayer requests, testimonials, and anointing (Simpson & King, 1999). Prayer requests or “verbal petitions for God’s assistance” (p. 45), emphasize that healing is a matter of religious faith (e.g., “I’ve got it laid in the Big Doctor’s hands”). Second, testimonials constitute personal accounts of God’s healing as a result of faith. Third, and less common, is the healing ritual known as an anointing. An anointing consists of church elders placing a dab of cooking oil on their hands before laying hands on the sick and praying over them. Appalachian families have been noted for “taking care of their own”, a quality that is believed to be associated with religious morals associated with being a “goodchristian” (Horton, 1984; MacAvoy & Lippman, 2001). Furthermore, the role of religion in Appalachian culture is perceived as a mechanism for encouraging the self-sufficiency of mountain communities:

“Religion as manifested in the various local churches tends to foster better communities by contributing to individual value formation, helps to meet social-psychological needs, and even, in some instances, provides an organizational base from which local people can solve community problems” (Carter, 1984, p.139).

These studies indicate that religion is a central aspect of rural Appalachian identity. One limitation of this line of research is that individual studies identify aspects intrinsic

religiosity (i.e., personal or private expressions of faith such as prayer) and extrinsic religiosity (i.e., public displays of faith such as church attendance) as part of the rural experience, but have not measured associations with identity (Genia, 1993). Given the previous review of the importance of religion in health contexts, religiosity will likely impact the ways communication about health and illness will be interpreted. It is expected that both personal and public aspects of religiosity will be associated with rural identity:

H1: Rural identity will be positively associated with religiosity.

Implications of Rural Identity for Health

Understanding how identity shapes attitudes toward health is essential to improve communication about health in rural environments. Rural health disparities are widely documented (Gamm, Hutchison, Dabney, & Dorsey, 2003; Glasgow, Wright Morton, & Johnson, 2004; Ricketts, 1999a), but only a handful of studies attempt to investigate how rural identities influence health outcomes. Elliot-Schmidt and Strong (1997) have suggested that physical ability is a dominant health value in rural settings, which likely stems from the largely physical nature of work available. Consequently, “health” in rural locales is socially constructed to mean the absence of disease. Similarly, Horton (1984) claims that disability and illness are considered to be a normal part of aging in rural areas. This type of health value system translates into healthcare that is focused on delivering acute care and chronic disease management rather than the maintenance of good health (Coster & Gribben, 1999).

Previous health communication research on the sun protection behaviors of migrant farm workers found that rural audiences' concept of health was found to coincide with work and barriers to work in order to promote health conflicted with these conceptions ("if he showed up wearin' a straw hat, I knew I wasn't gonna hire 'im because he would spend more time chasing that hat than workin'") (Parrott, Steiner, & Goldenhar, 1996). In addition to work-related concerns, rural farming communities rely on the expectancies of their families to guide their health behaviors (Parrott & Lemieux, 2003). The Behavioral Adaptation Model advanced by Parrott and colleagues (1998) demonstrates that expectancies, knowledge and perceived knowledge to adapt behavior may be a more useful framework than traditional health care models for understanding the effectiveness of health messages in rural settings. For example, the family network plays an important role in increasing the confidence of rural farmwomen in their ability to perform breast self-exam (Egbert & Parrott, 2001). These studies suggest that people who live in rural areas have a perspective on health and healthcare that is reflective of their environment and may influence their perceptions of message that originate outside the rural context.

H2: Rural identity will be positively associated with perceived credibility of a message source.

Messages designed for rural audiences must account for the cultural and environmental factors that will influence their effectiveness. One common strategy for increasing the cultural sensitivity of health messages is the use of metaphors. The

following overview of perspectives on metaphor identifies relevant literature to guide the construction of culturally appropriate health messages.

Overview of Perspectives on Metaphor and Persuasion

Metaphors, as previously defined, frequently occur in our everyday conversation, thus attracting the scholarly interest across disciplines such as linguistics, anthropology, sociology, cognitive psychology, and epistemology and the philosophy of science (Ortony, 1993a). In the field of communication, a plethora of research has been devoted to understanding the ability of metaphor to enhance persuasion (Jaffe, 1988; McCroskey & Combs, 1969; Sopory & Dillard, 2002a; Sopory & Dillard, 2002b). In this way, metaphor is seen as a tool for enhancing persuasive outcomes. Specific outcomes of interest typically include whether people pay attention to the message, whether it is comprehended, whether the message was successful in reinforcing desirable attitudes or changing undesirable ones, and whether this change in attitudes results in behavior change (McGuire, 1972; Miller, Burgoon, & Burgoon, 1984; Petty & Cacioppo, 1996).

Despite the extant literature on figurative language which provides complex and conflicting views on what metaphors are and why we use them (Ortony, 1993b), research on message design has largely regarded metaphor as an implied comparison between two dissimilar entities that results in the qualities of one entity being transferred to the other (Sopory & Dillard, 2002a). Defining metaphor as an implicit comparison is considered to be a comparative view of metaphor, and is often represented simply as “A is B” (Hitchon, 1997; Petrie, 1979; Sopory & Dillard, 2002b). This is a rather basic approach to the study of metaphor, but it is useful for establishing a common vocabulary. Metaphors are

commonly said to have three components, where A is referred to as the “target” or “tenor,” B is called the “source” or “vehicle” because it carries meaning to A, and the shared characteristic between A and B labeled the “ground” (Hitchon, 1997).

While parsimonious, the comparative view of metaphor limits somewhat the scope of meaning that can be generated by a metaphor. Petrie (1979) argues that in order for a comparison to be reasonable, comparisons must occur within a particular cognitive structure. In other words, an individual must have a preexisting knowledge derived from experiences, education, or culture of the similarities between A and B in order to correctly identify the metaphor ground. Alternatively, interactive metaphors do not assume that the recipient has an existing knowledge of the similarities between A and B; instead, the message recipient is forced to use nonlinguistic contextual knowledge to interpret the comparison (Petrie, 1979). In other words, interactive metaphors *create* similarities, which signal a change in cognitive structure and thus the acquisition of new knowledge (Petrie, 1979).

Active metaphors evidently hold greater potential for the creation of new knowledge, but they also seem to be more open to misinterpretation. Indeed, variability in cultural knowledge appears to have enormous potential for a message source and recipient to perceive a different ground for a particular metaphor. The cancer as war metaphor illustrates the potential for misinterpretation of the metaphor ground. For example, one interpretation of the similarity between war and cancer might be perceived as achieving victory (increased quantity and quality of life) through battle (treatment). An alternate similarity that could be drawn from the metaphor given a less positive view of

militarism includes exorcising one evil (cancer) with another (toxic treatments) (Teucher, 2003).

While culture is likely to influence how metaphors are interpreted, the exact nature of the relationship between culture and metaphors is a source of contention between scholars who ascribe to cognitive models and those who support cognitive linguistic models. One way of thinking about culture and metaphor is articulated by cognitive linguists, Lakoff and Johnson (1980). The authors of the frequently cited text *Metaphors We Live By*, argue that metaphors play a central role in shaping human understanding (i.e., cultural knowledge). They posit that many commonly used metaphors relate to larger image schemas which develop from common human experience, and thus represent universally shared understanding. One illustration of this idea can be found in what cognitive linguists refer to as orientational metaphors.

Oriental Metaphors

Oriental metaphors use human cultural and physical experiences with spatial arrangements (e.g., up-down; in-out; front-back) to give concepts meaning, and that cultural values are revealed through the relationship between the abstract concept and its spatial assignment (Lakoff & Johnson, 1980). For example, the abstract concept “more” is generally regarded as “up,” which is based on the physical experience of adding objects to pile and observing the level of objects going up. The “more is up” association is revealed through common metaphors such as “my income *rose* last year” or “the number of books printed each year keeps going *up*.” Although Lakoff and Johnson (1980) posit that image schemas generally cut across cultures, they acknowledge that the

specific composition and valence of a metaphor in relationship to a specific schema can vary from culture to culture. Cognitive science views the relationship between culture and metaphor somewhat differently. This approach is illustrated using the superior organization view of metaphor, a derivative of the structure mapping model.

Superior Organization

The superior organization view holds that metaphors evoke semantic associations that ultimately influence attitudes toward a topic. Metaphors require message recipients to identify the similarities between two dissimilar entities (Gentner, 1988). The similarities (or attributes) between the metaphor and the central argument form connections or pathways (Read, Cesa, Jones, & Collins, 1990). The presence of multiple pathways helps to organize the message and make the reasoning more coherent. The clarity and coherency of the message helps the logic remain salient, which in turn aids in persuasion. For example, in the previous example of cancer as war, the metaphor has helped shape understanding of the disease as something that is long in duration but can be “beat” through aggressive medical tactics.

Thus, the persuasive ability of a metaphor is dependent on the audience. Audiences with high knowledge of the target are typically more persuaded by the metaphor than audiences with low knowledge of the target. Prior knowledge of the target helps a receiver understand the organization of the message and identify the ground (pathways) that connects the target and the base. Thus, consideration of the cultural identity of the audiences for whom a metaphorical message is intended will help explain the influence of metaphorical messages. Effective metaphors will be those in which the

message recipient is able to identify the intended similarities connecting the target and the base.

Cultural Critique of Metaphor

Quinn (1991) disagrees with the notion that image schemas (and thus metaphors) play such a primary role in shaping human understanding. Instead, she argues that reasoning is shaped by culture, and that cultural knowledge is the basis for creating and interpreting metaphors. She explains this position in terms of her own research on metaphors and the American model of marriage by saying, “It is not the metaphors [people] use for marriage...but the cultural model they have of it, that constitutes the dilemmas people reason about and frames the solutions they reason to” (p.77). In this example, the cultural model of marriage in America is based on the transferal of a culturally-based conception of love onto the institution of marriage, which then structure marital expectations such as the beliefs that marriage should be shared, mutually beneficial, and lasting. Metaphors for marriage, then, emerge from cultural understandings of what concepts are associated with marriage in this culture. For example, the statement “It [the marriage] was stuck together pretty good,” uses metaphorical language (“stuck together”) that demonstrates knowledge of the American cultural ideal that marriages should be lasting (Quinn, 1991).

Although scholars have differing opinions regarding the exact nature of the relationship between language and culture, there is overwhelming support for the powerful connection between the two. While this relationship is evident in everyday conversation, such describing expectations for marriage, it is rarely acknowledged as a

contributing factor to medical or health-related outcomes. The reality is that metaphors are one way that language shapes our perceptions of and experiences with illness. Thus, cancer comprises an arena in health communication where metaphors have been used and misused in both the public and interpersonal realms.

Metaphor as a Tool for Communicating about Health

The communication literature has reflected a growing interest in exploring the use of metaphor in health contexts, ranging from understanding how patients make sense of their illness, improving provider-patient communication, and enhancing health education (Bowker, 1996; Gibbs & Franks, 2002; Hutchings, 1998; Morgan, 1997; Sopory, 2005). For example, the Environmental Protection Agency has created a metaphorical message in conjunction with the Ad Council to communicate the seriousness of childhood asthma to the public. The text of the message states: “When I have an asthma attack, I feel like a fish with no water. –Jesse, Age 5”. The accompanying visual is a goldfish thrashing its body in a few drops of water. There are many potential interpretations of the similarities between the fish and the child. One similarity is that a child having an asthma attack lacks oxygen, just as a fish without water lacks oxygen. In this way, the metaphor helps explain biologically what is happening when a child has an asthma attack. Another potential similarity between the two is the severity of outcomes. A fish will die if kept out of the water for a long period of time, just as untreated childhood asthma can be associated with adverse outcomes, including death.

There are several features of metaphors that make them attractive to health communicators. First, metaphors have been demonstrated to be an effective persuasion

tool in interpersonal communication (Sopory & Dillard, 2002a; Sopory & Dillard, 2002b). Second, metaphor construction and interpretation is intricately tied to cultural knowledge. Thus, metaphor can often seem like an appropriate way to enhance the cultural sensitivity of a message or serve as a subtle means of audience segmentation (Kreuter & McClure, 2004). As the following passage demonstrates, some scholars contend that metaphor is particularly appropriate in instances where cultural diversity is a salient issue:

Reaching culturally diverse groups with messages vital to disease prevention and trying to convince group members to alter their behavior to safeguard their health may sometimes require tools that transcend explanatory language. Explanatory language tends to isolate and fragment, to describe one event followed by another in linear fashion. Figurative language tends to synthesize and combine; it can unite different levels of thought, feeling, and behavior into a holistic picture that gives a rounded perspective; and it draws on such unusual vehicles as culturally specific metaphors, e.g., idiomatic sayings or proverbs, stories, or songs that express aspects of folk wisdom in plain but effective terms (Freimuth, Linnan, & Potter, 2000).

Despite this glowing endorsement, some messages that incorporated metaphor for the purpose of being culturally sensitive have completely failed. One particular example is a safer sex PSA used in Ghana that attempted to compare a rain storm with an AIDS storm, with vague and confusing references about protecting oneself (Johnson, Flora, & Rimal, 1997). There is little research to explain in a systematic way why certain health messages containing metaphors succeed and why some fail. However, a review of the literature revealed at least two recommendations for health messages utilizing metaphor.

First, Phillips and colleagues (1996) recommend avoiding exaggerated metaphors. Exaggerated metaphors are commonly used to discredit harm-reduction approaches to

health promotion. For example, on a 1994 episode of *Good Morning America*, the director of the Massachusetts tobacco control program compared switching from cigarettes to smokeless tobacco (considered by some to be a harm-reduction technique) to jumping off the 3rd floor of a building rather than the 10th. The public recognizes this and similar claims (e.g., shooting oneself in the foot rather than the head) as exaggerated because it is commonsense that the personal injury caused by jumping off a building (i.e., immediate death) will be more severe than the risks associated with the use of tobacco (i.e., chance of illness and possibly premature death). Perceiving a health message as exaggerated is likely to negatively influence perceptions of credibility, or believability, of the source and/or the message (for a review of source and message credibility, see Metzger, Flanagan, Eyal, Lemus, & McCann, 2003). With regard to the message source, exaggeration is likely to decrease perceptions of trustworthiness, which has been found to be one of the primary dimensions of source credibility. Message credibility is derived from both structure (i.e., organization) and content (e.g., information quality, language intensity), with the latter most likely to suffer when a message is perceived as exaggerated. It has been suggested that the process of judging a health message to be inaccurate will hurt the credibility of that specific message as well as subsequent messages from the same source and/or on the same topic (Phillips, et al., 1996).

Second, Sopory (1995) maintains that health messages should attempt to reflect the message designers' understanding of the core knowledge structures (called conceptual metaphors) that guide health behavior and create messages that are congruent with those conceptual structures. To illustrate, Sopory argues that SEXUAL ENCOUNTER AS A

RIVER JOURNEY, a submetaphor of Lakoff and Johnson's (1980) conceptual metaphor of RELATIONSHIP IS A JOURNEY, can be used to explain alcohol use and sexual activity in the college context. The conceptual metaphor of RELATIONSHIP AS A JOURNEY to explain relationships and sex was supported by formative research that referenced movement ("...and then you make a move..."; "If you are drinking or stoned you are more easily led."). Sex was seen as a milestone in relational journey, and sometimes as the ultimate journey destination ("And if you don't hit a road block [while initiating sex] you just keep going."; "And then there's always that kind of brick wall you can run into once you get all naked and everything. You are heading down the road toward sex and one person just decides no."). Alcohol emerged as a factor that accelerated the time it took to reach the milestone or destination in the journey ("Right, I just think that when if you are in a relationship with someone and you drink with them you will have sex sooner if you drink together than if you didn't."). Finally, comments indicated that sex and relationships are conceived as river journeys, as opposed to those by land or air, because of its fast, one-way direction or movement ("I think a lot of times you are drunk and just go with the flow."; "...you get swept up...").

According to Sopory (1995), health messages promoting safer sex or a reduction in alcohol consumption that have conceptual metaphors other than SEXUAL ENCOUNTER AS A RIVER JOURNEY at their core may not be as effective as those that do. For example, a message encouraging students to keep their feet firmly on the ground would go against the grain of the conceptual metaphor. A potentially more effective approach would be to build messages from the conceptual metaphor, with

recommendations like “steering the correct course.” This case study illustrates the challenges of creating effective health messages for commonplace behaviors that are heavily value-laden.

Taken together, these studies have important implications for metaphorical health messages. The first implication is that metaphorical health messages must be carefully constructed to ensure the intended comparison is both obvious and factually accurate. Metaphors that are perceived as being confusing or exaggerated will be ineffective and perhaps harm future health promotion efforts (Phillips, et al., 1996). The second implication is that culturally based knowledge structures guide health behaviors and health messages need to be consistent with those structures. Health messages using metaphors that are culturally mismatched to the intended population have little hope of achieving the intended attitude or behavior change (Sopory, 1995). However, it is unknown if utilizing these principles will result in more persuasive messages. Knowledge in the area of metaphor and persuasion has largely resulted from studies that compare messages containing figurative language to messages using literal language or numerical values (Sopory & Dillard, 2002). Rather than simply assume all metaphors are equal, there is a need for research that investigates what qualities will make a particular metaphor more persuasive with a particular audience as compared to both literal language and other types of metaphors.

Cancer Clinical Trials: A Context for Use of Metaphorical Language

A primary source of tension between patients and physicians is the use of technical terminology in the medical consultation (Mishler, 1984a; 1984b). Research

suggests, for example, that patients lack even a basic vocabulary to discuss cancer detection techniques with their physicians. One study reports that only 39% of participants were able to correctly identify breast self-examination, mammography, and biopsy as various forms of cancer screening (Chapman, Abraham, Jenkins, & Fallowfield, 2003). In this same study, approximately half of the participants did not understand common terminology used to describe cancer (e.g., “spots”), a diagnosis of cancer (“your lymph nodes are positive”), and the spreading of cancer (e.g., “tumour is progressing”) (Chapman, et al., 2003). Even when individuals think they understand medical terminology, they are often unsure of the correctness of their interpretation. For example, in a study conducted by Alden and colleagues (2000), nearly all the participants reported that “malignant tumour” meant cancer but demonstrated lack of certainty in their response. These communication problems have been documented using samples drawn from the larger population, making it unclear whether these issues are exacerbated with underserved audiences.

The inability to achieve shared meaning can also occur as a result of physicians’ failure to use appropriate medical terminology in conversation. One way this can occur is through the use of figurative language such as metaphors. Many physicians and surgeons use euphemisms for cancer, assuming that their patients understand their true meaning (Alden, Gilbert, & Webb, 2000). Three types of metaphors that have been identified in the literature as being used to explain cancer-related concepts include the military (Sontag, 1989), gambling (Jenkins, Leach, Fallowfield, Nicholls, & Newsham, 2002), and technology (Jenkins, et al., 2002). The most pervasive of these is the military

metaphor, primarily used to address cancer research and treatment broadly speaking. Military metaphors became popular among scientists in the 1880s with the identification as bacterial as agents for disease that “invaded” and “infiltrated” the body (Sontag, 1989). The military metaphor entered the public sphere in 1971 with the passage of the National Cancer Act (NCA), a document that declared President Nixon’s “War on Cancer” (The National Cancer Institute, 1999). Since then, Sontag (1989) posits that the military metaphor has pervaded all aspects of the disease, sometimes replacing more precise medical terminology. She uses the example of tumor growth. Instead of cancer cells multiplying, they are often said to “invade” a body, a body lacking the “defenses” necessary to destroy the tumor.

According to Sontag (1989), the language used for cancer treatment also bears military overtones. Radiotherapy uses language akin to aerial warfare, such that patients are “bombarded” with toxic rays. Chemotherapy is the biomedical version of chemical warfare, with physicians administering poisons to patients with the hope of “killing” the cancer without killing the patient. Finally, and perhaps most importantly, people with cancer are often treated as soldiers in this war on cancer, with individuals who engage the “fight” or “crusade” against cancer often being referred to as cancer “victims” (Sontag, 1989). While the military metaphor is common for explaining many kinds of cancer treatment, it is often replaced by a traditional medical metaphor with references to gambling when the potential treatment option under consideration is a randomized cancer clinical trial.

Clinical Trials Defined

Clinical research studies are the primary way new treatment therapies are developed. There are four types or stages of clinical research that investigate the use of a new medication or therapy with humans. Phase I research studies are conducted with a small number of patients and are intended to test the safety of a new therapy with humans. Phase II research studies involve a slightly larger pool of patients and focus on identifying the correct dosage of a medication. Phase III research studies compare patients using the new medication or therapy to patients using the current standard of care. Phase IV research studies monitor the long-term outcomes associated with the drug. Phase III research studies are unique compared to the other phases because participants are frequently randomized to condition. Randomization means that patients are assigned by chance to one of two or more treatment groups. Thus, although patients in Phase III trials are given a choice whether or not to participate in the trial, they typically do not have a choice as to which of the treatments being tested in the trial they receive. Strategies to communicate this reality to cancer patients are needed.

Public Attitudes toward Clinical Trials

The challenges posed by the clinical trials context are complicated by the public dissemination of both negative and positive views of medical research conducted with human participants through the media. For example, safety issues associated with clinical trials came to the fore in September of 1999 when Jesse Gelsinger died while participating in a gene therapy experiment at the University of Pennsylvania (Stolberg, 1999). More recently, the media covered the 2001 clinical trial tragedy at Johns Hopkins

Medical Center when a healthy 24-year-old, Ellen Roche, died after participating in a study on asthma. A third example is the cover of the April 22, 2002 edition of Time magazine that read, “How medical testing has turned millions of US into human guinea pigs.” The article went on to describe the sordid past of clinical trials, including the three studies that are now widely recognized for their abuses to human participants. The most notorious of the three was a research project in 1930’s on the progress of untreated syphilis where African American men with the disease were not given penicillin, even after its efficacy as a treatment had been established. The second was a 1950’s study designed to investigate the psychological effects of LSD where soldiers in the U.S. Army were not informed that they were exposed to a psychedelic drug. The third project studied the human immune system by injecting prison inmates and the terminally ill with live cancer cells (Lemonick & Goldstein, 2002).

While it is important for the public to understand the ethical issues and potential health risks inherent in clinical trials, they must also understand the role that clinical trials play in developing new treatments for diseases such as cancer. One study demonstrated that the media can play a powerful role in increasing awareness about clinical trials. For example, the New York Times printed an article on the promising new antiangiogenesis drug, Endostatin, approximately a year and a half before the phase 1 trial began (Kolata, 1998). Despite concerns that the positive media coverage of Endostatin would give potential participants an unrealistic level of hope, a study conducted with patients who enrolled in the trial found that individuals who first heard about the trial through mediated channels were five times more likely to correctly understand the purpose of the

trial than individuals who learned of the trial from another source, including their physician (Pentz, Flamm, Sugarman, Cohen, Ayers, Herbst, Abbruzzese, 2002).

Clinical Trials & the Underserved

Despite the large number of people who have cancer, many clinical research studies have difficulty recruiting a sufficient number of participants for a trial (Emanuel, Schnipper, Kamin, Levinson, & Lichter, 2003). Although approximately 20% of individuals with cancer are eligible to participate in clinical research, only 2-3% actually do (Emanuel, et al., 2003). Such low participation rates in clinical trials often results in the delay of new treatments from reaching cancer patients. In addition to difficulty recruiting a sufficient number of patients, clinical trials are also plagued with problems associated with enrolling participants that are representative of the population that will likely receive the new treatment. Many scholars have expressed concern about the fact that clinical trials regularly under-represent medically underserved groups, such as low-income persons, older adults, racial/ethnic minorities, and rural residents (Di Maio & Perrone, 2003). Even when underrepresented groups are included in a clinical trial, many studies do not include a large enough sample for statistical comparison to be made with the majority group (Hall, 1999). This can have serious consequences for trial results, which can only be generalized to the degree that the research participants are representative of the full spectrum of people suffering from the disease (Di Maio & Perrone, 2003).

Factors that have been associated with low rates of clinical trials participation include older age, low-income, membership in a racial/ethnic minority group, and rural

residence (Brown & Topcu, 2003; Curry & Jackson, 2003; Hall, 1999; Hutchins, Unger, & Crowley, 1999; Lewis, Kilgore, Goldman, Trimble, Kaplan, Montello, et al., 2003; Swanson & Ward, 1995; Yee, Pater, Pho, Zee, & Siu, 2003). The reasons these individuals are routinely underrepresented have been attributed to reduced access to health care (Ross, Grant, Counsell, Gillespie, Russell, & Prescott, 1999) and culture (e.g., Paskett, Cooper, Stark, Ricketts, Tropman, Hatzell, Aldrich, Atkins, 2002).

Rural populations. The Appalachian region includes 410 counties in 13 states (New York, Pennsylvania, Ohio, Maryland, West Virginia, Virginia, Kentucky, Tennessee, North Carolina, South Carolina, Georgia, Alabama, Mississippi) surrounding the spine of the Appalachian Mountains. Although the majority of low-income, rural residents of the geographical area known as Appalachia are Caucasian, they share the high burden of cancer and low rates of clinical trials participation that are typically associated with membership in a racial or ethnic minority group in the United States (Friedrich, 2002). The designation of Appalachia as medically underserved stems from the classification of two-thirds of Appalachian counties as rural, with 35% classified by the Appalachian Regional Commission as distressed or severely distressed based on 1988 measures of per capita income, employment, and levels of poverty (Couto, 1994a).

Overall cancer rates in Appalachian states exceed the national average (Appalachia Cancer Network, 2003; Huang, Wyatt, Tucker, Bottorff, Lengerich, & Hall, 2002). Although the majority of rural Appalachians are not racial minorities, they are designated as a medically underserved population due the high burden of disease in the region and the relative lack of resources available to residents (Couto, 1994). Like other

groups that experience health disparities, lack of access and cultural factors have been identified as causing and perpetuating these disparities.

Older adults. For many years, older adults have been systematically excluded from participation in clinical trials, especially for cancer. Many trials have protocols that excluded older adults because of co-morbidities that would complicate or possibly confound their research design. This has contributed at least in part to findings that adults over the age of 65 make-up only 25% of clinical trials participants, although it is estimated that older adults represent 63% of the U.S. population of patients with cancer (Hutchins, Unger, Crowley, Coltman, & Albain, 1999). Scholars have argued that research designs that exclude older adults because of coexisting diseases that would not interact with the treatment being studied are unjustified. Their rationale is that older adults comprise the majority of people being treated for cancer; thus, the patients who are expected to benefit from the treatment under study will likely have normal age-related organ impairment or coexisting illnesses (Hutchins, et al., 1999).

There are several other potential factors influencing the low rates of participation of older adults in clinical trials including financial barriers, institutionalized ageism, and personal attitudes toward clinical trials. In terms of financial barriers, it is significant that Medicare does not pay for treatments that are considered experimental (Hutchins, Unger, Crowley, Coltman, & Albain, 1999). However, this fact is not likely to explain the whole of this age-related disparity. A study of clinical trials participation in Canada, where medical costs are covered regardless of whether the treatment is experimental, found that older adults are also underrepresented in Canadian clinical trials (Yee, Pater, Pho, Zee, &

Siu, 2003). Another potential explanation for the differences in clinical trials enrollment between younger and older adults is ageism. Patients are generally referred to clinical trials by their primary care physician, and physicians are reported to be reluctant to refer older adult patients to trials (Comis, Miller, Aldigé, Krebs, & Stoval, 2003; Kenemy, Peterson, Kornblith, Muss, Wheeler, Levine, et al., 2003). Physicians report being reluctant to enroll older patients in clinical trials for a variety of reasons including the aforementioned concern about co-morbidities, the possibility of increased toxicity, inconvenience for patients, lack of social support, time required for patient enrollment and follow-up studies, and personal preference for conventional therapy (Yee, et al. 2003). Although a patient's physical ability to participate in a clinical trial is a reasonable concern, clinical trial research has demonstrated that age alone is not sufficient indicator for restricting trial participation (Muss, Woolf, Berry, Cirrincione, Weiss, Budman, et al., 2005). The tendency for physicians to ignore scientific evidence on this point in favor of personal judgments of the ability of an older adult patient to participate in a trial demonstrates the pervasiveness of ageism in the medical realm.

In addition to considering an older adult patient's ability to complete a trial, and a physician's willingness to enroll an older adult patient in a trial, it is also important to examine older adults' interest and willingness to participate in clinical research. An Australian study has found that older women are significantly more likely to decline to participate in a clinical trial than younger women (Ellis, Butow, Tattersall, Dunn, & Houssami, 2001). A survey conducted in the U.S. found slightly different results. Younger adults were more likely to have positive attitudes towards clinical trials than

older adults. Nevertheless, the majority (53%) of older adults (age 65 or older) did report a positive attitude toward participating in a trial (Comis, Miller, Aldigé, Krebs, & Stoval, 2003). Other research has supported the idea that older adults are generally in favor of participating in clinical research. Kenemy and colleagues (2003) found that, while older patients with stage II breast cancer were significantly less likely to be offered a trial than younger patients with stage II disease, there were no significant differences between younger and older patients accepting participation in a trial when it was offered. Finally, Brown and Topcu (2003) report that approximately 75% of both White and Black older adults said they would participate in a clinical trial if they were diagnosed with cancer. Although the results are slightly conflicting on this issue, at the very least we can be sure that the low enrollment rates of older adults in clinical trials are a combination of factors including finances, institutionalized ageism, and personal attitudes toward clinical trials. A number of studies have tried to understand the latter issue in more detail. The primary premise of this line of research is that improving patients' understanding of clinical trials will ultimately improve recruiting outcomes.

Recruitment to Cancer Clinical Trials

Explaining a disease like cancer is difficult, but helping patients understand the nature of cancer clinical trial is likely to be even more challenging as a result of the multifaceted nature of clinical research. Thus, physicians must be able to explain terminology related both to cancer treatment and research design. Due to the complexity of this scenario, it is not surprising that research has found that individuals enrolled in clinical trials frequently 1) do not understand the rationale for trials, 2) have poor recall

of information actually provided, and 3) are sometimes impeded from making fully informed decisions due to physiological and psychological difficulties (Brown, Butow, Ellis, Boyle, & Tattersall, in press). In order to counteract the trends of low participation rates in trials and situations where patients do not appear to fully understand the clinical trials process, scholars have begun to turn their attention to knowledge of and attitudes toward clinical trials.

Cancer clinical trials education is one particular health issue where metaphors are used extensively. One potential reason for the abundance of metaphorical messages in this realm is the great difficulty associated with translating highly technical medical and scientific terminology into language that can be easily understood by lay audiences (Jenkins, Leach, Fallowfield, Nicholls, & Newsham, 2002). Some scholars have suggested that the under-representation of medically underserved groups can be partly attributed to the language used by physicians during the recruitment process. Indeed, research on patient understanding of the clinical trials process appears to allude that certain commonly used metaphors are problematic for many individuals. Thus, the aim of this study is to elucidate the potential connection between language and the under-representation of certain groups by investigating whether common metaphors used to recruit patients to clinical trials elicit negative emotional responses from people living in rural Appalachia.

Metaphor use in clinical trial recruitment

Several studies have identified that the language used by physicians to explain the clinical trials process is a contributing factor to reduced participation in trials (e.g.,

Curbow, Fogarty, McDonnell, Chill, & Scott, in press; Fleissig, Jenkins, Fallowfield, 2001; Jenkins, Fallowfield, Souhami, & Sawtell, 1999; Llewellyn-Thomas, Thiel, Sem, & Woermke, 1995). One strategy that physicians often use to improve understanding and comprehension of clinical trials concepts is the use of metaphor. As discussed previously, using and interpreting metaphors is an activity that relies on shared cultural knowledge. Thus, if two people share a similar cultural background, a metaphor is likely a good vehicle for creating and sharing meaning. However, for two individuals who do not share a similar cultural background, the use of metaphor could be potentially disastrous. Metaphors are a primarily strategy for explaining the process of randomization in a Phase III randomized trial.

There are two reasons for focusing on the randomization aspect of a clinical trial. First, randomization is a highly technical term for which there are no “lay language” synonyms, which has naturally created an interest in creating metaphors. Second, although metaphorical language is most likely used to explain many aspects of the clinical trials process, previous research has focused specifically on metaphors used to describe the process of randomization.

Metaphor in communication about randomization

According the CancerWEB On-line medical dictionary, randomization refers to the allocation of individuals to groups, e.g., for experimental and control regimes, by chance. Due to scientific nature of the term, the first exposure that most people will have to this word will probably be in clinical trials educational literature or a discussion with a health care provider or family member about a clinical trial. This means that health

providers are charged with describing randomization using language that makes sense to the patient. Given this challenge, providers often turn to metaphorical language to help bridge the knowledge gap. One study estimates that health care providers use similes, a particular type of metaphorical language, to describe the randomization process about a third of the time (Jenkins et al., 1999). The most common similes health care providers use includes describing randomization as “like the toss of a coin”, “like the lottery”, and “picking a number from a hat”. The prevalence of gambling metaphors to describe randomization was emphasized by a study that asked physicians to select one out of seven descriptions of clinical trials that best reflected the one they used when actually discussing clinical trials with patients (Jenkins, Leach, Fallowfield, Nicholls, & Newsham, 2002). The second most commonly chosen phrase was, “One you have agreed to enter the trial, a computer will perform the equivalent of tossing a coin to allocate you to one of two methods of treatment.”

Health care providers undoubtedly use traditional medical metaphors, such as those that refer to gambling, because they are believed to be accurate and familiar explanations for relevant concepts. However, the use of such analogies may actually bias patients against participation in clinical trials. Indeed, it is not hard to imagine that patients may extrapolate the randomization analogy to the clinical trials experience in general such that they conclude that clinical trials participation is akin to “gambling with one’s health.” This notion is supported by data from focus groups on attitudes to randomized trials. For example, one of the participants said: *“It’s a lottery, because they don’t know whether you’re going to go through those six months for nothing...It’s like a*

Russian roulette” (Ellis & Butow, 1998, p.529). The association between gambling and clinical trials was made explicit by a participant who said: *“It’s still a gamble. It’s the unknown...You say, ‘we’re not sure’. ‘we think’. You use all those words...You still have doubts”* (Ellis & Butow, 1998, p.530).

The uncertainty introduced by the term randomization is thought to be partly responsible for the poor rates of clinical trials participation. In fact, several studies have found that aversion to randomization is a primary reason for opting not to participate in a clinical trial (Curbow, Fogarty, McDonnell, Chill, & Scott, in press; Fleissig, Jenkins, Fallowfield, 2001; Jenkins & Fallowfield, 2000; Jenkins, Fallowfield, Souhami, & Sawtell, 1999; Kemeny, et. al, 2003; Llewellyn-Thomas, Thiel, Sem, & Woermke, 1995). A telephone survey of randomly selected Kentucky residents provides further evidence that the semantic value of the word “randomization” is significant. In the survey, 73% of participants were willing to participate in experimental form of therapy with indeterminate benefit, however, only 39% were willing to participate in a randomized clinical trial of two therapies given the same scenario (Valentino, Andrykowski, & Wood, 1999). It is clear from this study that individuals have dramatic, unfavorable reactions to term randomization, but the reason for this reactance has yet to be explored.

Because randomization has been found to be such a critical factor in clinical trials decision-making, Jenkins et al (2002) conducted a survey of patient and lay preferences for describing clinical trials. They provided each participant with seven possible descriptions for randomization. Of the choices, the two most preferred explanations for randomization were 1) A computer will randomly allocate you to one of two possible

methods of treatment, and 2) A computer not a doctor will decide which of the two treatments to give you, decision will be random and due to chance alone, and not based on the patient's or doctor's decision. The results of the study indicated that preferences for describing randomization were not uniform across participants, with the differences being attributed to age. Participants under the age of 60 disliked the following statement the most: "You will be allocated to one of two treatments with equal chances of each treatment being the one you will receive," while participants over 60 disliked the following statement the most: "A computer will perform the equivalent of tossing a coin." The qualitative data collected in reference to the latter definition revealed that participants did not like the example of "tossing a coin" because this explanation was "frightening," "trivializing," "too much like a prize draw", and "like a lottery-which of course it is." It is unclear from this study whether the discomfort with this analogy is a result of the use of the coin toss metaphor, or if it also reflected dislike of the reference to a computer.

If the participants were reacting to the technology element of the definition, "A computer will perform the equivalent of tossing a coin," then the intergenerational differences might be explained by the well-documented disparities that exist among age cohorts with regard to comfort with computers and Internet use. According to Brodie, Flournoy, Altman, and Blendon, (2000), 31% of people under age 60 use computers at home to get health information, compared to only one in ten adults over the age of 60. The higher level of computers use among younger adults to access health information on the Internet may also make them more comfortable with references to computers in the

context of randomization. If so, then other medically underserved groups that typically have lower computer and internet use, such as African Americans, low-income, and low-literacy audiences may also disprefer technological explanations of issues like randomization (Brodie, Flournoy, Altman, Blendon, 2000; Miller, 2001). In sum, the way a concept like randomization is explained influences the way people think about that concept. The use of a gambling metaphor in the previously mentioned study did not achieve its intended result because the audience reacted poorly to the comparison. Perhaps a more strategic use of metaphors to explain randomization may improve on outcomes of clinical trials communication efforts.

RQ 2: How do rural, low-income older adult women respond to conventional metaphors for randomization that refer to gambling and technology in the context of cancer clinical trials?

RQ 3: What alternate metaphors for describing chance might be appropriate for rural, low-income, older adult women?

A Model for Investigating Metaphor Use in Clinical Trials

One of the unique features of the clinical trials context is that, unlike many other health domains, there is no single recommended response. For example, public health can say with great certainty that the health benefits of wearing a seatbelt while riding in a motor vehicle far outweigh the potential dangers. Thus, many campaigns have been designed around the notion of promoting the recommended response of wearing a seat belt. The same is true for behaviors such as smoking cessation, firearm safety, and sun protection. In clinical trials, however, there is not and there cannot be a universal

recommended response that can be promoted to the public. The appropriateness of a clinical trial for a particular individual is based on a number of complex factors, rendering a simple message advocating that people with cancer enroll in clinical trials inadvisable.

The other extreme is a situation in which the general public is uninformed about the process of discovering and approving new treatments for cancer. Thus, people who are not explicitly offered a trial may never even consider trial participation, even in cases when they would benefit. Those that are presented with the option of a clinical trial may be unmotivated to consider it as a result of being exposed only to negative aspects of clinical trials. The element of risk is an important feature of clinical trials that must be evaluated. However, the discussion of risks can sometimes be misleading to patients, particularly in situations where they lack awareness and understanding on the topic of clinical trials. For example, patients may not realize that although Phase III trials entail a degree of risk, the potential for adverse side effects may or may not be greater than the risks posed by therapies already approved by the Food and Drug Administration.

Thus, the goals of health communication efforts in the realm of clinical trials is not to directly accrue more patients to experimental research but to develop, apply, and refine theoretical perspectives that will help predict and explain effective approaches for communicating with lay audiences about clinical trials. To this end, the purpose of this study is to investigate the use of metaphor as a strategy to explain the element of randomization in Phase III clinical trials to rural, low-income, older adult women. Women were chosen as the target audience for this investigation because rural family structures often place women in the role of caregiver, making women an important

audience for messages about their own health as well as the health of their family members such as their spouse, aging parents, or ill relatives (Mulder, Shellenberger, Streiegel, Jumper-Thurman, Danda, Kenkel, et al., 1999).

One model that provides a parsimonious framework within which to consider the goals of clinical trials communication is McGuire's (1972) six-stage model for understanding information processing. His approach suggests that a change in health behavior (or behavioral intentions) is predicated on six sequential steps. The first step is presentation of the message, which refers to assuring that the intended audience is exposed to a health message. The second step is attracting attention to the message. This requires that audiences attend to what is being presented. The third step is comprehension of the message. People must understand what it is they are expected to do. The fourth step is yielding to the message. Yielding essentially means agreeing with the message and the arguments presented. The fifth step is retaining the position of yielding until the opportunity arises to enact the recommended response. The last step is behavior (or behavioral intention). Failure to advance to the next step at any level is considered to be detrimental to ability of the message to promote behavior change. For example, if the audience becomes confused or distracted at step 3 (comprehension), they cannot be expected to subsequently agree with the recommendation or enact that recommendation.

Research on audience segmentation suggests that motivation to process health messages can be increased by carefully designing the features of the message, such as the channel, source, and supporting evidence. Previous research has not yet established what message features are most appropriate and effective for communicating with rural

audiences; however, the studies reviewed earlier suggest several potential directions that will be explored further herein. First, there are some indications of rural identification, meaning that people living in rural areas view themselves as being distinct from the urban counterparts. As healthcare services become increasingly urbanized, rural identification may help explain gaps related to which populations seek care. Such gaps may be associated with a second important aspect, the perceived credibility of a care provider or message source. Third, studies suggest that religiosity plays an important role in rural health. The organized aspects for religion (e.g., church) may provide a socially acceptable way to share personal problems while the less interactive aspects (e.g., personal prayer) may provide a mechanism for increasing personal efficacy to deal with distressing events. Rural identification, perceived credibility of message source, and religiosity will each be explored for their influence on message outcomes.

A unique feature of McGuire's model is that some of the steps can be investigated using both traditional questionnaire approaches along with physiological measures. The three steps that lend themselves most directly to a triangulated approach to data collection include attention to the message, comprehension of the message, and yielding to the message. Next, the steps in McGuire's model will be discussed with a focus on cancer message design and the applicability of physiological measurement to the study of message design.

Attention

The first step in McGuire's model, presentation, is an important feature of message dissemination. Message design studies, however, are typically constructed such that the

presentation of the message is held constant, with messages being delivered in controlled settings. Although the presentation of the message to the participant can be controlled, whether a participant chooses to pay attention to the message cannot be. The previous review of the literature on metaphor suggests that figurative language, especially novel comparisons, increases attention to messages. In the cancer context, patients are unlikely to expect a metaphor to be a part of a medical explanation. When it does occur, it should be a significantly novel experience to encourage greater attention to the particular topic under discussion.

In addition to questionnaire measures, effects of a message (i.e., attention, comprehension, yielding) can also be measured through physiological responses. The psychophysiology literature provides evidence that bodies respond physiologically to learning new information and processing emotion. Thus, physiological responses serve as means to observe knowledge acquisition and affective responses to a message.

Physiological responses to environmental stimuli are apparent through changes in heart rate and skin conductance activity (Bensafi, Rouby, Garget, Bertrand, Vigouroux, & Holley, 2002; Globisch, Hamm, Esteves, Öhman, 1999; Levy, Hausdorff, Hencke, & Wei, 2000; Reeves, Lang, Kim, Tatar, 1999).

The social influence literature generally supports the notion that metaphors would be valuable contributions to health messages across cultural identity groups. For instance, a crucial component of McGuire's information processing paradigm is attracting the attention of the audience. The use of vivid language, which refers to language that is typically emotionally interesting, concrete and imagery-provoking, and immediate in a

sensory, temporal, or spatial way, one tool used to attract attention to a message (Nisbett & Ross, 1980). Novel metaphors (i.e., metaphors that make a connection between two concepts that the message recipient had not previously considered) are considered a form of vivid language. Thus, when audiences are presented with a health message that uses a novel metaphor, the process of determining the intended relationship between the two concepts should increase attention to such a message. A potential problem with this line of reasoning is that not all novel metaphors may be perceived as appropriate in the medical context. A metaphor that is perceived as inappropriate for serious context may have the reverse effect on attention. Take, for example, the conventional medical metaphor, “Randomization is like the flip of a coin.” How a woman with a rural cultural identity will respond to that metaphor depends on whether they relate to the flip of a coin as a form of gambling or as a way to represent chance. If the associations revolve around the former, then religiosity may help explain the nature of that association. The associations that many Christian religions have toward gambling involve its “sinful” attributes, which would be expected to decrease attention to the message.

RQ4: Is rural cultural identity, perceived credibility, or religiosity associated with attention to randomization messages?

RQ5: Does attention vary when comparing low-income rural women’s responses to messages which use: (a) conventional metaphors, as compared to (b) cultural metaphors, or (c) a scientific definition?

Given that the majority of people diagnosed with cancer are older adults, it might seem logical that older people would be more likely to pay attention to health messages

about cancer. The aging literature, however, suggests that this may not be the case given findings that older adults demonstrate reduced attention to messages as compared to younger adults (Pesce, Guidetti, Baldari, Tessitore, Capranica, 2005). It has been suggested that this difference is caused by a decrease in the efficiency of the cognitive processes that help filter irrelevant stimuli and focus attention on target information (Persad, Abeles, Zacks, & Denburg, 2002). Thus, it is hypothesized that:

H3: Attention to a randomization message will differ according to age.

A third factor that may influence attention to a randomization message is knowledge of a personal or family history of cancer. Women who have had cancer are often informed that there is a chance that cancer will reoccur. Thus, the personal experience of diagnosis and treatment should be associated with increased attention to a message describing a treatment option that may arise in the future. Similarly, women who have not had cancer but has awareness of a history of cancer in her family should also be more likely to pay increased attention to the randomization message. Thus, the following research hypotheses are posed:

H4: A cancer history will increase attention to the randomization message.

Comprehension

The next crucial step in McGuire's model is for the audience to comprehend the message. Comprehension is predicated on a person paying attention to a message, so people who did not pay attention to the message would not be expected to comprehend it. For those that do pay attention to the message, metaphors should be effective tools for helping people understand a new concept like randomization according to the superior

organization view of metaphor. The logic is that comprehension will occur as the audience identifies the similarities between the ground and target. The SOV posits that the metaphor serves as an organizational tool that structures the message and makes it easier to understand and leads to increase comprehension of a message. However, cultural critiques of metaphor suggest that when two concepts are compared, not all people will perceive the same similarities between the two concepts. The reason for this is that people will perceive similarities based on their own cultural framework. Using the traditional medical metaphor, “Randomization is like the flip of a coin” as an example, a person can comprehend that metaphor as a form of gambling or as a way to represent chance. It is possible that religiosity or cancer history may be factors that influence how the metaphor is understood. This logic leads to the following research questions and predictions:

RQ6: Is rural cultural identity, perceived credibility, or religiosity associated with comprehension of a randomization message?

RQ7: Does a family or personal history of cancer history increase comprehension of a randomization message?

RQ8: Does comprehension vary when comparing low-income rural women’s responses to messages which use: (a) conventional metaphors, as compared to (b) cultural metaphors, or (c) a scientific definition?

H5: Comprehension of a randomization messages will differ according to age.

Arousal and Negative Affect

The literature on arousal as a social influence construct is voluminous and conflicted, with different definitions being applied in various contexts. In this study, arousal is defined as an index of “the extent to which an individual experiences a sense of energy or mobilization” (Dillard & Meijnders, 2002, p.313). The positive or negative valence of that energy is referred to as affect (i.e., emotion). Thus, once a person identifies connections or pathways between two concepts, those connections may create arousal. Arousal, in turn, may influence the persuasive qualities of the message (Johnson & Taylor, 1981). If the connections are perceived as pleasant in nature, the arousal will be positively valenced. If the connections are perceived as inappropriate or frightening, the state of arousal will be experienced as negatively valenced. Health messages on frightening topics such as cancer may be able to avoid activating high levels of negatively valenced arousal by being culturally sensitive.

Arousal has been measured using both heart rate and skin conductance measures (Globisch, et al., 1999; Levy, et al., 2000). Skin conductance generally indicates a heightened sense of arousal level. Heart rate has been used to interpret the valence of increased arousal, with disagreement as to what patterns indicate negative and positive emotions (Globisch, et al., 1999; Reeves, et al., 1999). Examples of how these constructs have been applied in the literature include a study that measured the physiological responses of subjects with both high and low animal fear to photos of snakes and spiders (Globisch, et al., 1999). For people who self-reported as being fearful of snakes and spiders, exposure to photos of these animals resulted in increased skin conductance

response and cardiac acceleration relative to neutral photos. Thus, increased skin conductance and increased heart rate were associated with arousing, unpleasant stimuli. The relationship between heart rate and emotional valence is someone contested. While some studies find that negatively valenced stimuli are associated with an increase in heart rate like the study conducted by Globisch and colleagues (1999), other studies find that negatively valenced stimuli is associated with a deceleration of heart rate (Reeves, et al., 1999). Increased arousal, however, is generally indicated by an increase in skin conductance.

Levy and colleagues (2000) studied the effects of exposing older adults to positive or negative stereotypes of aging through a series of four studies. Support was found for the hypothesis that exposure to negative stereotypes of aging would increase heart rate and skin conductance. All the studies indicate that skin conductance indicates whether a message is arousing, with higher levels of arousal being associated with increased skin conductance. Three of the four studies associated increased heart rate with negatively valenced stimuli and deceleration with positively valenced stimuli.

Previous studies in the clinical trials literature have found that increased comprehension of clinical trials materials do not always increase intentions to participate in clinical trials. One potential reason is that comprehension of a particular concept may be arousing, and that experiencing arousal interferes with the acceptance of the message. For example, the degree to which rural identity may influence a perception that a traditional medical metaphor is intimidating “gambling” or “gambling with one’s life” could potentially increase negative arousal. In addition to the interpretation that gambling

with one's life suggests danger, a religious background could influence interpretations that such a procedure is morally unjust. An additional factor that could influence affective responses is a personal history of cancer. Having such a history may be associated with strong emotional responses to particular types of message strategies for explaining randomization. For example, while some people who have had cancer appreciate metaphor as way of communicating about the disease, others believe it to be an inadequate and sometime dangerous communication tool. Using this reasoning, the following research questions are posed:

RQ9: Is rural cultural identity, perceived credibility, or religiosity associated with a negative affective response to a randomization message?

RQ10: Does a family or personal history of cancer influence negative affective responses to a randomization message?

To summarize, different types of cancer messages are likely to elicit differing affective responses. However, the degree to which a particular message strategy is associated with negative affect may be vulnerable to change across the lifespan. It has been suggested that older age is associated with a tendency to focus on the emotional content rather than the informational aspects of a message (Fung & Carstensen, 2003). Thus, as people age, responses to the affective component of a message may be intensified. This reasoning leads to the following predictions and research question:

RQ11: Do low-income rural women's affective responses to messages vary according to the presence of: (a) conventional metaphors, as compared to (b) cultural metaphors, or (c) a scientific definition?

H6: Negative affective responses to a randomization message will differ according to age.

Yielding

According to McGuire's model, paying attention to a message and understanding the message are precursors to determining whether or not they agree with the argument that was presented in the message. The degree to which a person is persuaded by the message is called yielding. Women who hear messages about randomization may be more likely to yield to messages on the basis of both the characteristics of the message and group memberships. For example, messages that contain cultural metaphors may be perceived as more credible and persuasive than messages that contain conventional metaphors. Similarly, it is possible that being highly religious or having a history of cancer may make someone more likely to yield to such a message. Thus, the following exploratory research questions are posed:

RQ12: Is rural cultural identity, perceived credibility, or religiosity associated with yielding to a randomization message?

RQ13: Does a family or personal history of cancer influence yielding to a randomization message?

RQ14: Does yielding differ according to age?

RQ15: Does yielding among low-income rural women vary according to the presence of: (a) conventional metaphors, as compared to (b) cultural metaphors, or (c) a scientific definition?

Behavioral Intentions

The last step in McGuire's model is behavior, or intention to behave in a particular way. The reality is that unequal rates of clinical trial participation among medically underserved groups can only be resolved by enrolling people from these groups in clinical trials. The decision to enroll in a clinical trial is a very complex one, requiring a consideration of personal, familial, and medical ramifications. Improved communication with medically underserved audiences should hopefully lead to change in attitudes and intentions that could potentially result in more people making an informed choice to participate in cancer clinical trials. It should be noted that the clinical trials context is somewhat unique with regard to the feasibility and ethical appropriateness of encouraging all people with cancer to enroll in a trial. A more reasonable and appropriate goal is to encourage understanding of clinical research in hopes of providing people with cancer an opportunity to make informed choices about their treatment or the treatment of loved ones. In such cases, measuring actual enrollment into a clinical trial may not be the best outcome against which to measure the success of an intervention. An alternative outcome is to measure behavioral intentions to seek out information about a trial should a situation necessitate the consideration of cancer treatment for themselves or a loved one. According to McGuire's model, behavioral intentions in the result of garnering the attention of an audience as well the audience comprehending and agreeing with the message. It was previously argued that rural cultural identity and religiosity would influence responses to messages with either a culturally appropriate metaphor for

randomization or a traditional medical metaphor at each of those steps. In keeping with that logic, the following research question is posed:

RQ16: Is rural cultural identity, perceived credibility, or religiosity associated with intentions to participate in clinical trials?

Previous studies on age and intentions to participate in clinical trials are somewhat mixed. Most studies have found that older adults express willingness to participate in clinical trials, although some have found that younger adults express slightly more interest in participation.

RQ17: Does intentions to participate in clinical trials vary when comparing low-income rural women's responses to messages which use: (a) conventional metaphors, as compared to (b) cultural metaphors, or (c) a scientific definition?

H7: Intentions to participate in clinical trials will differ by age such that pre-retirement women will express greater intentions to participate than will post-retirement women.

In a similar vein, previous research has not investigated the potential influence of a cancer diagnosis or a history of cancer on intentions to participate in clinical trials. It is unknown if cancer history would be associated with an vested interest improving treatment options thus making a woman more interested in participating in experimental research or if it would be associated with a preference for what is familiar, such as conventional forms of therapy when available. Furthermore, it would be useful to know if

cultural identity and religiosity have a differential influence based on cancer history. The following research question is intended to investigate this potential relationship:

RQ18: Will cancer history be associated with intentions to participate in clinical trials?

In addition to understanding what factors help to explain outcomes associated with exposure to a message such as attention, comprehension, arousal, yielding, and behavioral intentions among rural, low-income, older-adult women, it is important to look at the applicability of the model as a whole in this context for two reasons. One reason is testing the model with diverse populations may yield new insights on the role of culture in message processing. The second is that communication about clinical trials is complex, and the sequential nature of McGuire's model should lend itself to greater understanding about where the greatest difficulties lie. Thus, the final research question is:

RQ19: Do attention, comprehension, arousal, and yielding explain rural, low-income, older adult women's intentions to participate in cancer clinical trials?

Chapter 2

METHOD

Overview of Methods

The purpose of this study was to investigate whether metaphor is an effective tool for communicating complex health information, such as the meaning of randomized assignment to treatment in the context of a clinical trial, to rural, low-income, older adult women. The research questions and hypotheses posed in this study were addressed through two phases: 1) stimulus development, which included formative research interviews and focus groups to assess attitudes toward clinical cancer research and provide input on message development; and (2) a laboratory study involving self-report and physiological measures with a community-based sample.

Stimulus Development

The ultimate goal of the stimulus development phase was to develop videotaped messages explaining randomization so that they could be experimentally compared in the laboratory study. Because culture was hypothesized to influence the effectiveness of messages about randomization, extensive formative research was conducted to ensure one the messages was culturally appropriate and gain insight into additional ways clinical trial message design for rural, low-income, older adult women could be improved. These goals were accomplished through conducting formative research interviews and focus groups with rural, low-income, older adult women. The focus groups were intended to be the primary form of formative data collection, but given the lack of previous research with this population, preliminary data was collected through formative interviews. The

interview process was instrumental in piloting potential focus group questions and also provided an opportunity to gather in-depth data on rural identity. Specifically, the interviews yielded preliminary data on rural identity and the ways it may influence health, insights into the perceived efficacy of investigational treatments, and an alternate explanation for randomization. The focus groups that followed honed in on the perceived benefits of and potential barriers to participating in clinical trials and what factors would influence the treatment decision.

Because this study was intended to focus on low-income, older adult women living in Pennsylvania counties that are served by the ACCN, several criteria were established for the formative research. Participants were required to be an adult female over the age of 50 residing in a county classified as rural by the Center for Rural Pennsylvania (<http://www.ruralpa.org/ruralcounties.html>), with an income less than or equal to 200% of the HHS Federal Poverty Guidelines. The protocol for the formative research was approved by The Pennsylvania State University Office of Research Protections (IRB #18631).

Formative Interviews

Participants

Participants in the formative research interviews included eleven rural, low-income women who had been diagnosed with cancer. The women ranged in age from 55-84 years old ($M=70.3$). The majority of participants had been diagnosed with breast cancer, with the others reporting cancer diagnoses of the uterus, skin, colon, and brain. The average age of the cancer diagnosis was 61. Two participants were undergoing

treatment at the time of the interview for cancers that were considered to be “incurable.” All of the women self-identified as White and reported a combined family income less than or equal to 200% of the 2003 HHS Federal Poverty Guidelines.² The majority of the participants were married at the time of the interview ($n=6$), and almost all reported being active in either a Catholic or Protestant church.

Procedures

A primary aim of this project was to involve rural, low-income, older adult women living in counties served by the Appalachia Community Cancer Network (ACCN), formerly known as the Northern Appalachia Cancer Network (nACN). To achieve this goal, the investigator contacted a community-based cancer coalition affiliated with the ACCN to ask for assistance in identifying potential participants for the project. After being invited to attend a coalition meeting, the investigator gave a brief presentation about the purpose of the project, explained the inclusion criteria for the study, and asked the members of the coalition for their assistance with recruiting. The coalition members determined that each person present would each recruit one woman for the study, and that the names and contact information of interested women would be forwarded to the investigator. Thus, potential participants were contacted directly through coalition members, a technique congruent with nomination sampling procedures (Krueger, 1994).

² The Federal Poverty Guidelines are based on the number of people in a household. In 2003, a family of 2 would need to make \$24, 980 a year or less to qualify. The majority of participants ($n=6$) reported an income of \$10,001-\$20,000 a year. In 2005, a family of two would need to make \$25, 660 a year or less to qualify.

The coalition provided the contact information for seven potential participants. Four additional women who met the inclusion criteria but lived outside the targeted county were also admitted to the study. These women were referred to the study through the ACCN and an outside party. The principle investigator contacted each potential participant to verify her eligibility to participate in the study. The prescreening questions confirmed that each potential participant was over 50, had never participated in a cancer clinical trial, and that their annual household income was equal to or below 200% of the Federal Poverty Guidelines. Participants who met the study criteria were invited to participate in an interview at the time and place of their convenience.

Interviews were approximately two hours in length and were typically conducted in participant's homes and at local restaurants. Before proceeding with the interview, the women were given two copies of an informed consent document (see Appendix A). The investigator verbally emphasized several of the key points included on the consent form, including that the conversation would be tape-recorded, the interviewee could choose not to respond to any of the questions, and all responses would be kept confidential. The women were then asked to read through the document, sign and return one copy of the form, and keep one copy for their records. At the conclusion of the interview, the women were thanked for their time and compensated \$40 cash. The women were also offered a book produced by the National Cancer Institute entitled, "Cancer clinical trials: The basic workbook." The investigator pointed out that the book lists a toll-free number for the Cancer Information Service (CIS) and explained that the CIS could address any questions or concerns they might have about cancer or clinical trials.

Interview guide

The semi-structured, in-depth interviews were conducted using an interview guide (See Appendix B). The interview began with a brief introduction of the purpose of the research. Women were told that the government funded the study in order to learn about women's cancer treatment experiences as well as their opinions on ways to improve communication about cancer treatment options. The first set of questions focused on the rural experience, including the benefits and disadvantages of rural life and the degree to which identity is associated with residing in a rural area. Next, participants were asked to talk about their cancer diagnosis, concentrating on how treatment decisions were made. The final set of questions centered on cancer research studies, including overall impressions of clinical research to personal willingness to participate in experimental therapies. As part of this discussion, participants were asked to give their impressions of a series of definitions for explaining the process of randomization and suggest alternate explanations.

Data analysis

The digital audio recordings of the interviews were transcribed verbatim. The researcher masked the identity of the participants in the transcripts by replacing identifying information (i.e., proper names) with initials. Data from the interviews was analyzed using a grounded theory approach, which allows for the discovery of relevant categories during analysis (Strauss & Corbin, 1990). Preliminary categories were developed through repeated readings of the transcripts by the investigator. The output was then organized under each theme, and the categories re-evaluated for their

conceptual fit with the data. The investigator and a faculty member reviewed the alternate explanations for randomization generated by the participants. Each suggestion was evaluated on the basis of its conceptual match to random assignment, with the closest match being the one selected.

Results

The interviews yielded preliminary data on rural identity and the ways it may influence health, insights into the perceived efficacy of investigational treatments, and an alternate explanation for randomization. One objective was to identify whether identification as a rural resident influenced health. Although only a few participants identified themselves as Appalachian (with one person interpreting that label to mean “practically fresh out of the cave”), women used other terms to describe their rural identity. Participants used phrases such as “country people”, “people over the mountain”, and “the working class right here in our area” to describe people with whom they could identify.

A second goal was to assess attitudes toward clinical trials in general, and the perceived efficacy of investigational treatments in particular. Participants saw clinical trials primarily as an option of last resort. However, they generally had positive attitudes toward clinical research and believed they would participate in a trial if a doctor recommended it. Their enthusiasm was tempered somewhat by the possibility of being randomly assigned to treatment. Participants felt strongly that a doctor (and possibly in conjunction with the patient) should be able to decide which of the treatments being compared would be better for the individual.

The third objective was to determine whether current metaphors helped explain the idea of being randomly assigned to treatment and identify culturally-based metaphors that had the potential to be effective with a rural population. The metaphors identified in the literature (e.g., flip of a coin, drawing a number out of a hat) were perceived to “sound like gambling”, which for most participants had a highly negative connotation. Participants were asked to provide suggestions for better ways to explain “equal chance”. One participant suggested that equal chance was best represented by “some are born women and some are born men.” The research team deemed that the sex of a baby had potential to be an effective metaphor because it eliminated the “win-loss” component of gambling metaphors.

Formative Focus Groups

Participants

Four focus groups were held in three different counties served by the ACCN with rural, low-income, older adult women. Participants included 30 women over the age of 50 ($M=67.2$, $SD=9.65$) who reported an annual household income that was equal to or less than 200% of the Federal Poverty Guidelines.³ Approximately three-fourths (73.3%) of the women reported an annual household income of \$20,000 or less, with 4 (13.3%) unreported. Slightly less than half the participants had been diagnosed with cancer at some point ($n=12$, 40%). Education levels ranged from eighth grade ($n=2$) to post-graduate work ($n=1$), with the average education being a high school diploma ($M=12.63$,

³ One participant never confirmed that her income was within the guidelines even though she was aware this was a requirement of participation. She arrived late the focus group and simply joined in. She also failed to report her income on the questionnaire. Because there is no way of knowing if she was qualified to participate in the study, her comments during the focus group have been eliminated from analysis.

$SD=2.25$). Participants reported attending religious services on an average of five times a month ($M=5.32$, $SD=4.65$).

Procedures

Based on the success of participant recruitment using nomination sampling procedures for the formative interviews, a similar process was used for focus group recruitment. The investigator contacted three cancer coalitions affiliated with the ACCN and requested their assistance with the project. The investigator attended a coalition meeting in each county and gave a brief presentation about the purpose of the project, explained the recruitment guidelines, and requested assistance with recruiting participants for the project. Each coalition agreed to participate, and requested that the investigator provide them a summary report of the project's findings in exchange for their participation. The investigator supplied the coalition with fliers and postage to facilitate the recruitment process.

Focus group recruitment through the coalitions worked differently than in the interview study. In two of the three counties, a member of the coalition involved in health services (i.e., community health educator) took the primary responsibility for recruiting all the focus group members. In these coalitions, the primary recruiter was compensated \$10.00 for each person who participated in the focus group. In the third county, a lay coalition member took primary responsibility for recruiting participants. The coalition member requested that the compensation for recruiting participants for the focus group be donated to the coalition.

The coalition members were instructed to provide the investigator with the names and telephone numbers of potential participants at least 48 hours prior to the focus group. In all but a few cases, the investigator was provided this information and prescreened potential participants to ensure they met the study criteria. If the woman did not meet the study criteria, the investigator thanked the individual for her interest, explained which criteria she did not meet, and invited to refer someone else to the study. Whenever feasible, the moderator then provided a reminder phone call to each potential participant the evening before the focus group.

The focus groups were held in community rooms at an Aging Services building, a local hospital, and a mall. Each focus group lasted approximately 2 hours. Upon arrival to the focus group location, participants were given two copies of an informed consent form (See Appendix C) that explained the purpose of the study, their rights as a research participant, and that the focus group would be audio and video taped. Women were asked to sign and return one copy of the consent form and keep the other for their records. Participants were then asked to complete a short questionnaire (see Appendix D) assessing basic demographic information, general health status, and knowledge about clinical trials. After consenting to participate, a light meal was served and the women were given approximately 20 minutes to socialize.

Moderator guide

The researcher began each focus group by giving a brief introduction to the research. Participants were told that the purpose of the study was to hear their “thoughts and opinions regarding cancer” and that they would not be receiving information about

cancer. They were then reassured that there are no right or wrong answers, and that it was important for each focus group member to participate in the discussion. The researcher pointed out that the discussion was audio and videotaped, but that comments would remain confidential and only used for research purposes. In order to establish credibility with the participants, the researcher gave a brief introduction of herself to the participants, including an explanation of her background, educational goals, and interests regarding cancer in rural settings. The participants then followed suit with their introductions.

The moderator guide was designed to stimulate discussion in three main topic areas. The first focused on general issues related to cancer, such as what cancer is, what causes cancer, how cancer develops, and how medicines for cancer are developed. The second focused on experimental therapies for treating cancer, including what a clinical trial is, the benefits and disadvantages of clinical research studies, and reasons a physician might suggest a clinical research study to a patient. The final topic area explored reactions to metaphorical and non-metaphorical ways of explaining random assignment to treatment in the context of a clinical research study. The different explanations presented to the group were derived from previous research on randomization, patient education materials on clinical trials, and input from women who participated in the formative interviews. Examples of the metaphorical explanations given include “Randomization is like ‘the flip of a coin’, ‘drawing a number out of a hat’, and ‘the roll of a die’.” Examples of non-metaphorical explanations given include “Randomization means that one of two methods of treatment will be chosen by chance,

and not by a decision made by the patient or the doctor” and “Randomization means that you will be assigned to one of two treatments with equal chances of each treatment being the one you will receive.”

Based on the findings of the formative interviews, each topic area was introduced through a brief narrative written at a 7th grade reading level to help stimulate discussion. The first narrative introduced the main character (a woman named “Pat) and began a discussion about general issues related to cancer. The researcher drew a female stick-figure on tablet paper and said, “This is Pat, and all we know about her is that she has cancer. I’d like to talk about how she came to have cancer. What do you think are some of the reasons why she might have gotten cancer?” The second narrative was crafted to transition the group discussion from cancer in general to cancer treatment options, including clinical trials. The moderator read the following narrative out loud after distributing a hard copy to each participant:

Now, I’d like to read you a short story about a woman named Pat. Pat is not a real person, but the decision that Pat has to make could be similar to a decision that you or a family member or friend may have to make in the future. Pat is a 65 year old woman who lives in [name of specific town where the focus group was held] who was just diagnosed with cancer. Pat’s doctor has informed her that she needs to have a mastectomy. After her surgery, Pat will need follow-up treatment. The doctor has given Pat two choices for her follow-up treatment. One option is for Pat to take tamoxifen for five years to help prevent the cancer from coming back. Pat also has the option of participating in a clinical trial, which is another name for a medical research study.

The third narrative was intended to accomplish two goals. First, it provided a straightforward example of being randomized to a treatment condition. This understanding would allow participants to determine what constitutes a “good”

explanation for that process. Second, it provided more information on Pat's health and specific details about the Phase III clinical trial Pat is considering. The formative interviews identified health status (co-morbidities and other medications) and the treatment differences between the two groups as two factors that are extremely important to treatment decision-making. Thus, the narrative specifically mentioned that Pat had no major health problems with the exception of cancer and was based on a clinical trial comparing two groups taking the same drug for a different period of time. This decision was intended to reduce the focus on the efficacy of one drug versus another and increase attention to efficacy of a trial using random assignment to condition. The trial description was based on a Phase III study found using ClinicalTrials.gov called, "Prolonged Tamoxifen compared with shorter Tamoxifen in treating patients who have breast cancer" (ClinicalTrials.gov identifier NCT00003016). The moderator distributed the following narrative to each participant and read it out loud to the group:

The doctor explains to Pat that only healthy women over the age of 50 without any major health problems other than cancer are accepted into this study. Because Pat meets all of these requirements, she has the choice of whether to be in the study or not. When Pat asks the doctor to explain more about the research study, she learns that some women in the study will take tamoxifen for five years and some will take tamoxifen for 10 years. The purpose of the study is to see if taking tamoxifen for ten years is better, worse, or the same as taking tamoxifen for five years in preventing the cancer from coming back. The doctor also explained that this is a randomized clinical trial, which means that if Pat chooses to join the study, she can't choose which group she wants to be in. Instead, every woman who participates in the study will be assigned randomly to the group of women taking tamoxifen for five years or the group of women taking tamoxifen for ten years. Instead of telling Pat that she would be put randomly to one of the groups, the doctor could have explained randomization in other ways. I am going to read you other ways of saying the same thing, and I'd like you to tell me if you like or don't like them.

At the conclusion of the focus group, the participants were thanked for their contribution to the research and compensated them \$40.00 cash for their time and participation. In addition, participants were given the option to take home patient educational materials provided by the National Cancer Institute on the topic of clinical trials. The moderator made sure each woman was aware that the booklet contained a toll-free information line (i.e., 1-800-4-CANCER) if they had any questions about clinical trials as a result of the focus group discussion.

Data analysis

The focus group proceedings were transcribed verbatim using the digital audio and video recordings. The researcher masked the identity of the participants in the transcripts by replacing identifying information with initials. Data from the focus groups was analyzed using a grounded theory approach, with preliminary categories developed through repeated readings of the transcripts by the investigator. The output was then organized under each theme, and the categories re-evaluated for their conceptual fit with the data.

Results

The two primary goals of the formative research were to identify salient attitudes toward clinical trials, and to identify how lay audiences interpret clinical trials terminology. Participant attitudes toward clinical trials included both positive and negative elements. On the whole, participants demonstrated an understanding that medical research with animals was limited and that further research with humans is necessary. The women identified both individual and societal benefits associated with

participating in a clinical trial. They felt an individual could benefit from a clinical trial if there was a possibility of receiving free medical treatment, especially if a person was under- or uninsured. The benefit to society was the potential of contributing to medical knowledge that could help future generations (especially children and grandchildren). One participant suggested that people might be more likely to participate in a trial if they perceived themselves as part of a community:

I think it's important to know, too, that apparently the patient — there is some aspect here as to whether the individual sees himself as an individual or part of the whole community, like whether or not you are the type of personality that, as M was saying now, "I don't want to be in a study. Just give me my medicine," and others would say, "If this would help someone else," so it would be important, to, to — I don't think you can start doing testing on hospital patients or cancer victims but somehow you target ...
(woman from I focus group)

Despite identifying positive aspects of clinical trial participation, participants reported that they associate the term "clinical trial" with people being treated like "guinea pigs." This association appears to be linked to the common belief that a person in a cancer clinical trial could receive a placebo or "sugar pill" instead of receiving treatment. The following comments illustrate the belief that cancer clinical trials sometimes deny treatment to people that need it:

Okay, you volunteer to do this, but what if you're the unlucky one [not] to get any medicine? And you're just living every day thinking maybe you're going to get better, but you're not taking any medicines that actually help you. (participant from I focus group)

... A while back, I would think right way about a clinical trial, I'd be thinking, what if I'm the person that's only getting the placebo? I'm not getting help and I don't know I'm not getting any help. That part of it would bother me. (participant from S focus group)

Confusion about the role of randomization in a Phase III clinical trial appears to contribute to the misunderstanding that some participants in a treatment trial do not receive treatment. For example, participants in each group were presented with the following statement: “Randomization means that you will be assigned to one of two treatments with equal chances of each treatment being the one you receive.” The fear of receiving a placebo was reflected through a participant wondering if the “chance” associated with randomization meant there was a chance a person would be in a group that didn’t receive treatment at all.

The aspects of clinical trials terminology that were addressed in the focus groups included a preference for “clinical trial” versus “research study” as well as definitions for randomization. With regard to the former, participants unanimously supported referring to clinical research as “research studies”. The reasons given go beyond simple preference to suggest that the two terms have different connotations. A person in one group acknowledged that a clinical trial and a research study mean the same thing, but another followed up by saying, “If it’s a study, you feel more confident.” (I focus group). Other comments suggest that the term research study emphasizes the knowledge to be gained from participation, such as: “[A] research study sounds like a school things....It’s out there, it’s not as invasive somehow” and, “[A research study] takes you out of the hospital and puts you in a classroom or something.” (I2 focus group). In a similar vein, using the word ‘research study’ may help potential participants feel more involved in the process, as evidenced by the following statement, “Yeah, you feel like it’s more important. You’re not a guinea pig. You’re involved in this research.” (S focus group)

In addition to exploring the connotations associated with the terms ‘clinical trial’ and ‘research study’, the focus groups were asked to provide feedback on metaphorical and non-metaphorical definitions for randomization. The metaphorical definitions were drawn from previous literature and compared randomization to activities such as flipping a coin, rolling a die, and drawing a number from a hat. The metaphorical definitions were generally dispreferred because participants perceived them to have strong references to gambling, as evidenced by the following comments:

I think maybe there are so many references to gambling, and I don’t like that part. I mean, we have the flip of the coin or the roll of the dice. That’s how it makes it sound like gambling, and I don’t like that. (I focus group)

I think about gambling for me is I don’t gamble because I think it’s a losing thing. So that’s why, I think the connotation for me is it sounds like it’s losing. I would ask for the doctor not to say anything that has to do with gambling. (I focus group)

In some cases, participants interpreted “gambling metaphors” to have a deeper meaning. Several participants felt that gambling metaphors are a mismatch to a grave situation like cancer. “I mean, it sounds as though it wasn’t — you’re talking about something serious, and you don’t want to flip a coin for something serious.” Other participants felt like the gambling metaphor minimized the value of people involved (“Makes you think like you’re only worth flipping a coin”). Finally, the use of gambling metaphors led participants to make statements such as, “I don’t want somebody to gamble with my life.”

Message Development

The results of the formative research led to the development of three stimulus messages designed to provide a brief overview of cancer clinical trials, with a focus on explaining randomized assignment to a treatment group. After reviewing the literature and patient educational materials on randomization from a variety of sources, the investigator identified metaphors and definitions as the two primary strategies used for explaining randomization. The investigator wrote scripts for the three stimulus videos, with the difference among them being the way randomization was explained. The first script explained randomization using a definition (i.e., “Randomization is a method used to ensure the research study is fair”), the second by using a convention metaphor (i.e., “Randomization is like the flip of a coin”), and the third by using the cultural metaphor identified in the formative research (i.e., “Randomization is like the sex of a baby”). The investigator then sent the scripts to a review panel consisting of community members, experts in both communication and clinical trials, and staff from the Office of Education and Special Initiatives at NCI. Each message was designed to keep the number of words and reading level (i.e., eight grade) constant. After numerous revisions, the script was finalized and sent to a local, family-practice physician who was acquainted with the researcher through a previous project and agreed to serve as the source for the messages.

A professional production company filmed, edited, and reproduced the DVDs. To ensure consistency among the conditions, procedures were followed to ensure that the videos were nearly identical. The script was filmed in sections so that the only difference among the videos was the definition of randomization. The first message utilized a

modified version of the National Cancer Institute’s technical definition of the randomization process. The italicized excerpt from the video was conceptualized as a “standard definition” approach:

Randomization is a method used to ensure the research study is fair. It means that patients are assigned by chance to different treatment groups. Each patient in a randomized study has an equal possibility of being put in one of these two groups. Sometimes there are more than two groups. In a treatment research study, a patient will either be in the group taking the new treatment called the treatment group or the group taking the usual treatment called the control or comparison group. Every patient in a randomized study will get treatment for his or her cancer.

The second message relied on a “coin flip” metaphor to explain randomization. The literature has identified gambling metaphors such as a coin flip as a common way that physician’s explain randomization to their patients. Chance is represented by the equal possibility of getting heads or tails. The italicized excerpt from the second video was conceptualized as a “conventional metaphor” approach:

Randomization is like the flip of a coin. The possibility of getting heads is the same as the possibility of getting tails. Each patient in a randomized study has an equal possibility of being put in one of two groups. Sometimes there are more than two groups. In a treatment research study, a patient will either be in the group taking the new treatment called the treatment group or the group taking the usual treatment called the control or comparison group. Every patient in a randomized study will get treatment for his or her cancer.

The third message incorporated findings from the formative research that suggested that conceiving a baby illustrates the role of chance without the negative connotations that might be associated with the coin flip metaphor (i.e., win/loss). Chance is represented by probability of conception resulting in a male or female baby (1 in 2). The italicized excerpt below was conceptualized as the “cultural metaphor” approach:

Randomization is like the sex of a baby. The possibility of a boy is the same as the possibility of a girl. Each patient in a randomized study has an equal possibility of being put in one of two groups. Sometimes there are more than two groups. In a treatment research study, a patient will either be in the group taking the new treatment called the treatment group or the group taking the usual treatment called the control or comparison group. Every patient in a randomized study will get treatment for his or her cancer.

The message was placed on a DVD, placed after a copy of a ten minute, educational DVD created by the National Cancer Institute entitled, “Cancer Trials: Because Lives Depend On It.” The NCI materials provided an overview of the clinical trials process, but did not describe randomization. The opening screen of the DVD showed two titles. The top title was the name of the NCI materials, with the title of the stimulus portion, called “Improving Cancer Care: A Local Doctor’s View”, below. To reduce the potential for technological errors, each DVD was designed to play the “Cancer Trials: Because Lives Depend On It”, which faded to a blue screen with the title “Improving Cancer Care: A Local Doctor’s View”, followed by the appropriate stimulus video for each condition. In other words, the titles on the opening screen did not serve as different “chapters” on the DVD; they simply served to orient the viewer that there would be two segments to the video. The DVDs were carefully edited and duplicated in such a way that the onset of the manipulation began at the same second in each condition. When the DVD was played, the first word of the manipulation (i.e., randomization) occurred at 688 seconds in the three experimental conditions.

Laboratory Study Methods

Study Design

A 4 message condition (control, definition, conventional metaphor, cultural metaphor,) between subjects pretest-posttest message design was used for the laboratory study. The study goal broadly conceived was to judge the value of a culturally appropriate metaphor for its effects on older, low income, rural women's responses to a message. Participants' responses were evaluated via self-report and collection of physiological data via the BIOPAC system for heart rate, galvanic skin conductance, and facial electromyographic responses while watching a video created by the National Cancer Institute. The purpose of the video, entitled "Cancer Clinical Trials: Because Lives Depend It," is to provide general awareness. As such, it provides a cursory overview of clinical trials, but does not introduce the topic of randomization. Participants in the control condition watched the NCI video only, while participants in the other three conditions watched the NCI video followed by one of three stimulus videos that were created for the project (see stimulus development for more details). Participants were assigned to one of the four study conditions (control, definition, conventional metaphor, cultural metaphor) using a random numbers table.

Participants

Recruitment

Women were recruited to participate in this study through both mass media and interpersonal channels. Mass media approaches emphasized the title of the research study, "Cancer C.A.R.E. in our Community," and included a posting on the Penn State

Office of Research Protections Study Listing website, ads placed in local newspapers, and pink flyers. Flyers were distributed senior centers, local retirement complexes, and grocery stores. Interpersonal approaches included talking with the activities director of local retirement complexes, who often introduced the researcher to long-term residents they believed might be eligible for the study. In two particular retirement complexes, residents who participated often actively recruited others from the same complex to participate. Approximately one half (45.7%) of the participants reported being recruited from a retirement complex using interpersonal/mediated channels, 22.9% through newspaper ads, 22.9% through interpersonal channels (excluding women living in retirement complexes), and 8.46% through flyers.

All mediated messages (i.e., newspapers, flyers) contained the home telephone number for the researcher as the contact information. When prospective participants called, the researcher verified that they met the following criteria: (1) over the age of 50; (2) annual household income was equal to or less than 200% of Federal Poverty guidelines; (3) they lived in a rural county; and (4) had never participated in a cancer clinical trial. One woman was deemed ineligible to participate at this phase in the screening because she was a non-native speaker of English and the researcher was unable to assess her eligibility for the study due to communication difficulties.

Women who met these criteria were deemed to be part of the intended population of the study and were asked the following additional questions to ensure they could participate in the physiological data collection: (1) Do you have a pacemaker?; (2) Do you wear wire-rim glasses?; and (3) Do you have a hearing aid? Due to safety concerns,

women with pacemakers could not complete the physiological data component of the research study, and were initially excluded. Because of recruiting difficulties, however, two women with pacemakers were permitted to participate but were not subject to physiological measures. A substantial amount of metal, such as the metal in wire-rimmed glasses, had the potential to compromise the quality of the physiological data collection. Thus, women with wire-rim glasses were admitted to the study if they reported being able to watch television at close range without glasses. Women with hearing aids were told that the study involved having two wires connected to patches on the face, and asked if they thought that would pose a problem (e.g., whistling) with their hearing aid. Women who reported no problems with their hearing aids were admitted to the study.

The researcher informed eligible participants that the research study was part of a doctoral thesis, and gave them an overview of the purpose of the research (i.e., “improve communication about cancer”), and described what the study involved (i.e., completing questionnaires, watching a video, and physiological monitoring during the video). The researcher explained that the physiological monitoring involved having patches put on their forehead, cheek, wrist, and ankles which would send information to a computer about how they react to a video about cancer treatment. The researcher assured them that the procedures were safe and not painful. Most potential participants were not concerned about the monitoring, with some explaining that they were not concerned because they go through a similar procedure when they visit their physician. One woman, however, did refuse to participate because she did not want to be connected to electrodes. Finally, the researcher informed potential participants that the study was funded by the government

and that they would be compensated \$65.00 for their time and travel. In several cases, participants wanted reassurance that the compensation came from the government, and not the researcher's personal finances. In one case, a participant initially withdrew from the study when compensation was mentioned because she believed a pharmaceutical company provided the money. The researcher assured her that the National Institutes of Health funded the study, and she ultimately agreed to participate.

The researcher made an appointment at a mutually agreeable time for participants and advised them not to wear pantyhose, metal jewelry, makeup, or lotion on the day of the research study so that the patches would stick to their skin. The researcher also determined if assistance with transportation to the study site was required. In cases where transportation was needed, the researcher assisted the participant in locating public transportation services (e.g., taxi, free transportation provided by the county for the elderly) or by personally providing transportation when feasible. Participants received a reminder phone call from the researcher the evening before their scheduled appointment.

Sample

Participants included 106 women living in a rural Pennsylvania county ranging in age from 50 to 94 ($M=68.10$, $SD=12.32$). Combined annual household income ranged from \$10,000 or less to \$25,001 to \$30,000, with three quarters (74.5%, $n=50$) reporting a combined household income of \$10,001 to \$15,000⁴. The majority of participants reported a high school education or less (52.8%, $n=56$), followed by votech and/or some

⁴ One participant did not provide specific income information, but confirmed she had an income of less or equal to the Federal Poverty guidelines during pre-screening. Because she was eligible for the study (i.e., low-income), her data was included in the analyses.

college (25.5%, $n=27$), college graduate (14.2%, $n=15$), and post graduate education (6.6%, $n=7$)⁵. The sample was almost entirely Caucasian (96.2%, $n=102$). The vast majority had never been diagnosed with cancer (81.1%, $n=86$), but the most people reported having at least one family member who had cancer (67.1%, $n=71$).⁶

Procedures

Data collection was facilitated by one of four trained, female graduate research assistants. Research assistants completed approximately 5 hours of training with the researcher on the laboratory study protocol, and approximately 10 additional hours of instruction with the Penn State Media Effects Laboratory coordinator on physiological data collection and Biopac hardware⁷. As part of the laboratory study training, research assistants were given a protocol that provided a suggested script for each step of data collection. Although they were not instructed to memorize the script, the researcher advised them on portions where wording was deemed important (e.g., saying the person would be “connected” to the equipment instead of “hooked up” to the equipment. Research assistants demonstrated their understanding of the equipment and the protocol by going through the study procedures at two separate occasions with a member of the research team to ensure the validity of the collection procedures. Additionally, researcher and peer observations were used periodically throughout the course of data collection to maintain consistency.

⁵ One participant did not report education.

⁶ 16% unreported ($n=17$).

⁷ Two of the four research assistants joined the study after it began; thus, the researcher conducted the initial part of their training on physiological data collection and the Biopac hardware.

Research assistants arrived to the laboratory approximately 45 minutes before the first participant arrived. Their first priority was to set up the computer, television, and DVD player and make sure the technology was working correctly. If problems were detected, they contacted the Media Effects laboratory coordinator to troubleshoot the equipment. The second priority of the research assistants was to post signs throughout the building to help participants locate the room where the study was being conducted. Their third priority was to check the names and cancer status of the woman scheduled for that day and assemble a packet of paperwork for each one (i.e., 2 copies of the informed consent form, pretest, posttest, and payment receipt).

Once a woman arrived to the laboratory, participation in the research study took approximately one hour. When participants entered the waiting room, the research assistant introduced herself, thanked them for coming, and invited them to sit down.⁸ The research assistant then provided an overview of the study, including the purpose, order of events, and the physiological measures using the following explanation as a guide:

We are so glad you are interested in participating in this study. The goal of this study is to help women with cancer by learning the best way to inform them about treatments. By participating in this study, you will be helping doctors communicate better with their patients, which can help improve medical care for everyone.

I would like to give you an overview of what is going to happen during the next hour so you know what to expect. First, I am going to give you a form to read and sign that describes your rights as a research participant (SHOW INFORMED CONSENT DOCUMENT). After that, I will ask

⁸ In some cases, two or more women came together to participate in the study. In such cases, each participant completed the entire study in the viewing room with the door closed. This procedure prevented the other women from interacting with the participant during the actual study and ensured that participants were not exposed to the questionnaire items or stimulus materials before beginning the study.

you to answer a few short questions (SHOW QUESTIONNAIRE). Next, we will go into the viewing room (POINT) where you will watch a thirteen minute video that will give you information about cancer research studies. While you are watching the video, we would like you to wear patches that will tell us things like how fast your heart is beating and your facial expressions. The patches are often used here at Penn State to learn how people respond to movies and television shows.

I will be helping you put patches that look like this (SHOW ELECTRODE) on your wrist, ankles, forehead, and cheek. Some people find the patches to be a little itchy, but I went through the study and I can assure you that they are safe and don't hurt. They have a little gel in the center will help the computer read your responses. First, I will rub a sponge over your skin like this (DEMONSTRATE), which will help the patch stay on your skin. Then, I will put the patches on (PLACE ELECTRODE ON THE SKIN) and connect them to the machine. I will also put these (SHOW GSR ELECTRODE) on two of your fingers. Like the patches, they will have a little gel on them. After you watch the video, I will help you remove the patches. (DEMONSTRATE REMOVING THE PATCH). I will ask you a few more questions and then we will be done. (SHOW QUESTIONNAIRE) This study is funded by the government, so when you complete the study, I will pay you \$65.00 for participating. The whole study should take about 1 hour to finish.

Participants were then given two copies of an informed consent document written at a 7th grade reading level (see Appendix I) to sign and date. When the participant completed and returned a copy of the consent form, the research assistant verbally administered the pretest questionnaire. The majority of the questionnaire asked participants to respond to questions using a five-point Disagree-Agree scale. For these questions, the participants were given a sheet of paper containing the words “Strongly Disagree”, “Disagree”, “Neutral”, “Agree”, and “Strongly Agree” written in 26-point Times New Roman font. This enabled participants to visualize and remember the response choices as each question was being read.

After completing the pretest, the research assistant explained that the next part of the study would involve attaching patches to the face, wrist, and ankle and then watching a short video on cancer treatment. She also explained that the patches are very sensitive to the natural oils on the skin, and requested that the participant wash her face and hands with a cosmetic cleansing cloth in the restroom. The participant was then led to the adjacent viewing room, and asked to sit in a chair positioned in front of a 27 inch diagonal television set. The research assistant explained that she would be rubbing a cosmetic sponge on each place that a patch would be located to help the patches stick to the skin while pointing to the forehead and cheek area of the face, a wrist, and both ankles. After the research assistant explained what would happen, she engaged in casual conversation to help the participant feel comfortable while she cleaned the skin, applied the electrodes, and connected the Biopac leads to each electrode.

Once the participant was settled in, the lab assistant then left the room and checked the computer insure that the physiological data was picking up responses from the woman and recording accurately. Problems with recording physiological data were largely the result of either improper software calibration or the ability of the electrodes to adhere to the skin of the participants. With regard to the former, the Media Effects lab coordinator was often available to help the research assistant troubleshoot and resolve hardware or software problems. The electrode problem was more complex, as loose or wrinkly skin proved to be an impediment to the adhering ability of general-purpose electrodes. The problem was largely resolved with the purchase of long-term electrodes, which offered a larger adhesive area. If data were not being recorded because of a loose

or missing electrode, the laboratory assistant would replace the electrode after cleaning the skin underneath for a second time.

Once all systems were judged to be functioning appropriately, the research assistant closed the door and began the stimulus video from the control room. The lights were also dimmed for the first couple of participants. However, several participants complained that the low lighting made them sleepy, and one woman even admitted to falling asleep during the video. Dimming the lights was subsequently eliminated from the protocol. After watching the video(s), the lab assistant re-entered the room, detached the electrode leads, and removed all electrodes. The lab assistant then verbally administered the posttest. When participants completed the final questionnaire, the lab assistant thanked them for their participation and compensated them \$65 cash for their time and travel. The lab assistant also offered the participant an opportunity to take fliers about the study to give to someone they know. After each subject, the research assistant recorded notes about the data collection process, including any relevant disclosures by the participant not captured through the questionnaires (e.g., participant sharing that she lacks interest in clinical trials as a potential treatment because she would refuse any type of treatment if she was diagnosed with cancer) as well as environmental factors that may have influenced the data collection (e.g., construction noises).

Physiological Data Collection

Physiological data were measured using Biopac MP30. The MP30 is a physiological data recording platform designed for use in the life sciences. Data were collected using one channel for each of the following four measurements: 1)

electrodermal activity; 2) electrocardiography (ECG); 3) surface electromyography (EMG) with electrode placement on the corrugator supercilii; and 4) surface electromyography with electrode placement on the zygomaticus major. Due to technical problems with the EMG measurements, only the results of the electrodermal activity and electrocardiography will be reported below.

Electrodermal activity (EDA)

EDA (originally referred to as galvanic skin response in the literature) measures increases in sweat production of the eccrine sweat glands to assess an organism's interaction with its environment, such as emotional responses and cognitive activity (Stern, Ray, & Quigley, 2001). While other sweat glands respond primarily to changes in temperature (i.e., sweat production is increased by warmer temperatures), eccrine sweat glands respond primarily to psychological stimuli (i.e., sweat production is increased by psychological arousal). Because eccrine glands are concentrated in the palms of the fingers and hands and soles of the feet, EDA was recorded by attaching transducers to the tips of the second and third fingers of the left hand. Two types of EDA were measured in this study: 1) *Skin conductance level (SCL)* and 2) *Skin conductance response (SCR)*. SCL is a measure of tonic arousal while SCR measures phasic responses to a stimulus.

Electrocardiography

Electrocardiography (*ECG*) ECG (also known as EKG) refers to a technique used to measure the electrical activity of the heart through recordings on the surface of the skin (Stern, et al., 2001). The output of electrocardiography, called ECG (or EKG), visually presents the electrical activity that influences heart rhythms. ECG is often used in

psychophysiology to identify abnormal heart rhythms such as high or low heart rate resulting from emotional excitement and mental activity. Early studies suggested that activation of the sympathetic nervous system resulted in an increase in arousal responses, including heart rate and EDA. Later studies demonstrated that these patterns vary widely, with heart rate and skin conductance often inversely related. Heart rate was recorded using a standard limb Lead II placement (electrodes on the right arm and left leg) because it is known to generate a larger R spike than Lead I and Lead III placements.

Manipulation Check

The messages in each condition either did not contain an explanation of randomization (control), or explained randomization using a definition (definition condition), or a metaphor (conventional and cultural metaphor conditions). The items used for the manipulation check assessed whether participants were able to 1) identify whether or not randomization was defined in the message, and 2) identify how it was defined. First, participants were asked if they remembered a doctor in the video explaining randomization. Participant responses ($N=103$) to this question (yes, no) were analyzed according to whether they were in one of the experimental conditions which used videos that included an explanation of randomization (definition, conventional metaphor, and cultural metaphor conditions) or the control condition which used a video that did not contain an explanation of randomization. The significant chi square value, $X^2(1, N=103)=8.00, p<01$ indicated that participants who were exposed to one of the three explanations of randomization were significantly more likely than those in the control condition to report that they remembered hearing about randomization.

Participants who remembered a doctor in the video explaining randomization ($n=80$) were then asked an addition three questions about how randomization was explained. The wording of each of three questions corresponded directly to the wording used in the definition, conventional metaphor, and cultural metaphor conditions. One question asked if random was explained as a method used to ensure the research study is fair. Responses (yes/no) were compared against whether a participant received a definition for randomization (definition condition) or not (control, conventional metaphor, or cultural metaphor conditions). Fisher's exact test was used due to one cell with a count less than five. The vast majority of participants (87.5% ($n=21$)) in the definition condition report that they remembered a doctor saying that randomization is a method used to ensure the research study is fair; however, but 75% ($n=42$) of people in other conditions incorrectly reported that they received this definition as well, ($p=.17$, Fisher's exact test).

Another question asked if the doctor explained random as being like the flip of a coin. Participant responses (yes/no) were compared to whether they received the conventional metaphor stimulus or one of the other three stimuli (control, definition, or cultural metaphor). People who received the conventional metaphor were significantly more likely to report the physician had compared randomization to the flip of a coin than participants in the other conditions ($p<.001$, Fisher's exact test). The third question asked if the doctor explained random as being like the sex of a baby. Again, responses (yes/no) were compared to whether a participant was assigned to the cultural metaphor condition or one of the other three (control, definition, conventional metaphor). The results of the

chi-square indicate that participants who were exposed to the cultural metaphor were more likely to report that the doctor explained randomization as being like the sex of a baby than participants in other conditions, $X^2(1, N=80)=24.65, p<001$.

Measures

Rural identity

Investigating rural health from an identity perspective requires an approach in which “place” becomes relative rather than concrete. In other words, rural identity is about perceiving connection and identification with the rural environment, including the people who live there. An extensive literature search revealed that previous studies of the rural experience lacked specific measures of rural identity. As a result, a measure of rural identity was adapted from a 20-item scale developed to measure urban identification with the German city of Heidelberg (Lalli, 1992). Items that were deemed confusing (e.g., “I have got native feelings for Heidelberg”) or unrelated to the purpose of the project (e.g., “I know Heidelberg so well that I would recognize the town on a photograph taken at any time”) were eliminated from consideration. From the remaining questions, six items were identified as being applicable to the intended population and modified to create a rural identity scale. The modified scale replaced the city name with “rural Pennsylvania.” The scale was comprised of the following items: (a) I feel at home in rural Pennsylvania; (b) I feel like I belong in rural Pennsylvania; (c) I am proud to live in rural Pennsylvania; (d) Living in rural Pennsylvania is an important part of who I am; (e) I would like to live in rural Pennsylvania forever; and (f) I identify with other people who live in rural Pennsylvania (see Appendix J).

Preliminary data analysis revealed that three of the six items (I feel at home in rural Pennsylvania; I am proud to live in rural Pennsylvania; and I identify with other people who live in rural Pennsylvania) were slightly peaked (i.e., the items exceeded the ratio of 2:1 for the kurtosis statistic divided by its standard error). The items were maintained as part of the scale due to their considerable face validity, approach that has been used in previous health communication research (Parrott, Silk, Dillow, Krieger, Harris, & Condit, 2005). The items were summed and divided by 6 to preserve the 1-5 scale ($M=3.99$, $SD=.82$; $\alpha=.93$).

Perceived source credibility

Participants rated the credibility of the physician who served as the message source using four items: a) The doctor in the video was just an actor playing a part (reverse-coded); b) The doctor in the video was honest; c) The doctor in the video knew a lot about cancer; and d) The doctor in the video cares about people with cancer. Participants responded to each question using a five point scale, with higher numbers representing stronger agreement ($M=4.06$, $SD=.44$; $\alpha=.70$).

Religiosity

Several participants in the formative research phase referred to God and religion as an important part of health decision making. The questions used to assess intrinsic and extrinsic religiosity were adaptations of Genia's (1993) revision of Allport and Ross' (1967) religiosity scale. The questions were originally adapted for a large, community-based project on human genetics in order to improve the design of the questions (i.e., avoid double-barreled questions) and to reflect input from a community group (Parrott,

Silk, Weiner, Condit, Harris, & Bernhardt, 2004). The reliability of the items was demonstrated through a questionnaire administered in various community settings in both the Northern and Southern regions of the U.S. (Parrott, Silk, Krieger, Harris, & Condit, 2004). The items used to assess intrinsic religiosity included: (a) I try hard to carry my religion over into all my other dealings in life; (b) my religion is what lies behind my whole approach to life; and (c) Religion answers many questions about the meaning of life ($M=3.91$, $SD=.88$; $\alpha=.85$). The four items used to assess extrinsic religiosity questions included: (a) An important purpose of prayer is to get relief from my problems; (b) Religion offers me comfort when misfortune strikes; (c) A primary purpose of prayer is to gain protection; and (d) An important purpose of prayer is to gain acceptance of misfortune. Participants responded to each question using a five point scale, with higher numbers representing stronger agreement ($M=3.76$, $SD=.84$; $\alpha=.84$) (see Appendix K).

Age

Participant age was assessed using a single item: How old are you? This variable was assessed in light of the literature reviewed previously demonstrating the potential for age differences in personal attitudes toward participating in trials as well as the likelihood of being offered a trial. While participant recruitment did not intentionally focus on specific age groups, the age distribution formed around retirement age (i.e., age 65). Retirement is an important milestone in the communication and aging literature because of the lifestyle and healthcare changes that are typically associated with it. This provided the opportunity to analyze the data in a manner that was sensitive to possible changes at different points in the lifespan. The continuous age variable was recoded into two

categories approximately equal in size. The first group consisted of women age 50-64 years of age ($n=47$, 44.3%). The second group included women age 65 and over ($n=59$, 55.7%).

Cancer History

Cancer history was assessed using two questions. Personal cancer experience was assessed using one item: Have you ever had cancer? Responses were categorized as yes (1) and no (0). Only a small percentage of participants reported having a past cancer diagnosis ($n=20$, 18.9%). A family history of cancer was assessed using the item: Do you have relatives with cancer? In most cases, participants responded by listing their relationships to people in their family who had been diagnosed with cancer (e.g., mother, brother). If they not initially respond in this way, the research assistant prompted them to do so. The vast majority ($n=89$, 83.96%) of participants reported at least one family member who had been diagnosed with cancer. The two items were combined to create one family history item where 0 represented participants with neither a personal or family history of cancer ($n=14$), 1 represented participants with a personal history of cancer, regardless of family history ($n=20$), and 2 represented participants with a family history of cancer, but no personal history ($n=72$).

Attention

General attention to the message was assessed using two items: (a) I listened carefully to what the doctor had to say; and (b) What the doctor had to say was very important. Participants responded to each item on a scale from 1 (strongly disagree) to 5

(strongly agree); ($M=4.17$, $SD=.49$; $\alpha=.68$). The items were then summed and divided by two to create an attention scale (see Appendix L).

Participants' heart rate during exposure to the stimulus video provided physiological data to assess the cognitive resources allocated to encoding the message. Heart rate was collected as milliseconds between R spikes in the QRS complex of the cardiac cycles. The millisecond data were then converted to average beats per minute (BPM) for each second of data collection, with data collected for a ten second baseline period prior to onset of each message and time-locked to exposure to the message. In order to account for individual differences in resting heart rate, the average baseline value for each participant was subtracted from the average BPM value for each second following the stimulus, for a total of eighteen seconds. This resulted in a BPM change score (BPM-baseline BPM) that served as the primary unit of analysis (Dio & Sundar, 2004). The change score for each of the eighteen seconds was averaged for each condition containing an explanation of randomization (definition, conventional metaphor, cultural metaphor) in order to test for significant differences by message type.

Randomization knowledge

Participants' knowledge of the randomization message was measured using five items on both the pretest and the posttest. Three items pertaining to randomization were derived from a larger scale of general clinical trials knowledge reported by Curbow and colleagues (2004): (a) In a clinical trial, randomization means that patients have an equal chance of being assigned to each treatment being tested; (b) Randomization means that patients in a clinical trial are allowed to choose treatment out of a list of options (reverse

coded); and (c) The goal of a clinical trial is to match people to the best treatment for them (reverse coded). Two additional items were taken from a seven-item general clinical trials knowledge scale described by Ellis and associates (2001): (d) Randomized trials are the best way to find out whether one treatment is better than another; (e) In a randomized trial, the treatment you get is decided by chance (See Appendix M). The items were originally reported as true/false items; however, the format of the questions was altered for this study to be sensitive to the intended population in this study. Participants were asked to respond to each item using a five point scale ranging from strongly disagree to strongly agree with a midpoint of neutral.

An examination of the distribution of responses for each item revealed a large number of neutral responses, particularly on the pretest comprehension items (see Table 2.1). This raised a concern that there were systematic differences among the conditions, with participants in some conditions being more apt to give a neutral response. Due to the number of cells with a count less than five (pretest=13; posttest=19), Cramer's V coefficient was used in cases without empty cells to measure the association between the likelihood of a participant answering neutral for each comprehension question and the stimulus condition on both the pretest and posttest. There were no significant differences in the number of neutral responses across the four conditions for any of pretest or posttest comprehension items (see Table 2.2).

Based on the lack of significant differences among the conditions for neutral responses, the midpoint data was included in subsequent analyses. The five items on the pre-test and the posttest Cronbach's alpha revealed extremely low reliability (pre-test:

$\alpha=.36$; posttest: $\alpha=.29$). For this reason, a single item (Randomization means that patients in a clinical trial are allowed to choose treatment out of a list of options) was used to measure pretest ($M=3.07$, $SD=1.09$) and posttest ($M=2.84$, $SD=1.14$) comprehension. This item was chosen because it had the lowest mean pretest comprehension score out of all the items. It was reasoned that an item with a pretest mean close to the midpoint of the scale should have had the most potential for participants to demonstrate an increase in comprehension on the posttest. Histograms revealed that the data for both the pretest and posttest questions had a bimodal distribution, suggesting that participants' answers reflected a yes/no pattern. For this reason, participant responses of strongly disagree, disagree, and neutral were recoded as 0 and responses of agree and strongly agree were recoded as 1. The result was that 44.6% ($n=41$) of the participants answered the pretest question correctly, and 40.2% ($n=37$) of the participants answered the posttest item correctly.

Randomization comprehension

Message comprehension was measured using both self-report and physiological measures. The self-report measure include one-item that stated, "Flipping a coin is a form of gambling." Participants were asked to respond to each item using a five-point scale ranging from strongly disagree to strongly agree with a midpoint of neutral ($M=3.58$, $SD=1.01$). Physiologically, comprehension was measured through changes in heart rate. According to Lang (1994), greater resource allocation to an external stimulus results in a slower heart rate. Thus, allotting the cognitive resources required for comprehension of a message should be evidenced by a deceleration trend in heart rate.

Table 2.1

Distribution of neutral responses on comprehension questions

	<i>Control</i>	<i>Definition</i>	<i>Con Meta</i>	<i>Cul Meta</i>	<i>Total</i>
<i>Pre-test</i>					
Patients have an equal chance	2	3	5	0	10
Allowed to choose treatment R	5	5	3	4	17
Match people to the best treatment R	0	2	2	0	4
Find out if one treatment is better	8	8	2	5	23
Treatment decided by chance	7	4	3	3	17
Total	22	22	15	12	71
<i>Posttest</i>					
Patients have an equal chance	1	1	0	0	2
Allowed to choose treatment R	4	2	2	2	10
Match people to the best treatment R	0	0	2	0	2
Find out if one treatment is better	2	2	1	2	7
Treatment decided by chance	5	2	1	2	10
Total	12	6	6	6	31

Table 2.2

Cramer's V: Comparison of neutral responses by condition

	<i>N</i>	<i>Value</i>	<i>Approx. Sig</i>
<i>Pre-test</i>			
Patients have an equal chance	92		
Allowed to choose treatment R	92	.07	.92
Match people to the best treatment R	92		
Find out if one treatment is better	92	.22	.20
Treatment decided by chance	92	.20	.32
Total			
<i>Posttest</i>			
Patients have an equal chance	92		
Allowed to choose treatment R	92	.13	.65
Match people to the best treatment R	92		
Find out if one treatment is better	92	.05	.96
Treatment decided by chance	92	.22	.23

Message induced affect

Self-reported affect was assessed using four questions measured on a five-point scale. Participants were to answer each question in response to the stem, “The doctor’s explanation of randomization made me feel...” The dimensions were: (a) sad; (b) worried; (c) tense; and (d) anxious, with higher numbers indicating greater affective responses. Reliability of the scale was calculated using Cronbach’s alpha ($M=2.37$, $SD=.75$; $\alpha=.82$) (see Appendix N). Participants’ skin conductance response during exposure to the stimulus video provided physiological data to assess the level of arousal experienced in response to the message. The frequency of spontaneous skin conductance responses (SCR) during the presentation of the message and the amplitude of largest spontaneous skin conductance response during the presentation was measured from peak to peak in millivolts over a eighteen second time period. Skin conductance level was calculated by extracting the mean SCL level for each second and plotting the values over time. Higher values indicate increased arousal.

Yielding

Yielding to the randomization message was assessed using four questions measured on a five-point scale. Participants were to answer each question in response to the stem, “The doctor’s explanation of randomization was...” The dimensions were: (a) persuasive; (b) convincing; (c) credible; and (d) accurate, with higher numbers indicating greater agreement. Reliability of the scale was calculated using Cronbach’s alpha ($M=3.98$, $SD=.57$; $\alpha=.86$) (see Appendix).

Behavioral intention

Behavioral intention to participate in a cancer clinical trial was measured using a four-item scale reported by Comis and colleagues (2003). Item wording was modified slightly to improve readability. The items included: (a) If I was diagnosed with cancer, I would want to participate in a clinical trial for a new treatment; (b) If I was diagnosed with cancer, I would want to participate in a clinical trial for my initial treatment; (c) If I was diagnosed with cancer, I would want to participate in a clinical trial if my initial treatment failed; and (d) If I did not have cancer and was asked to participate in a clinical trial to prevent cancer, I would be willing to participate. The scale demonstrated acceptable reliability on the pretest ($M=3.74$, $SD=.78$; $\alpha=.76$) and the posttest ($M=3.84$, $SD=.78$; $\alpha=.82$) (see Appendix O).

Data Analysis

Hypothesis 1 The first hypothesis predicted that rural identity would be correlated with religiosity. A Pearson's correlation tested the association between the rural identity scale and the intrinsic and extrinsic religiosity scales.

Hypothesis 2 The second hypothesis predicted that rural identity would be positively correlated with the perceived credibility of a message source. A Pearson's correlation was used to test the association between the rural identity scale and the perceived credibility scale.

Research Question 4. This research question asked if rural cultural identity, perceived credibility, or religiosity is associated with attention to randomization

messages. A Pearson's correlation tested the associations among rural identity, perceived credibility, and the intrinsic and extrinsic religiosity scales with the attention.

Research Question 5. The fifth research question asked if low-income, rural women's attention to a randomization message varies as a function of messages that use conventional metaphors as compared to cultural metaphors or a scientific definition. The research question was tested using analysis of variance with attention as the outcome variable, message strategy (control, definition, conventional metaphor, cultural metaphor) as the predictor, and intrinsic religiosity, extrinsic religiosity, perceived credibility, and pre-intervention behavioral intentions as covariates.

Hypothesis 3. The third hypothesis predicted that attention to a randomization message would differ according to age. The hypothesis was tested using analysis of variance with attention as the outcome variable, and message strategy (control, definition, conventional metaphor, cultural metaphor), age group (pre-retirement, post-retirement), and the interaction between the two as the predictors.

Hypothesis 4. The fourth hypothesis predicted that a history of cancer would increase attention to a randomization message. A one-way ANOVA was performed on attention comparing women with no history of cancer ($n=14$), women who have a personal history of cancer ($n=20$), and women with a family history of cancer ($n=72$).

Research Question 6. The sixth research questions asked if rural cultural identity, perceived credibility, or religiosity is associated with comprehension of a randomization message. A Pearson's correlation was used to determine if extrinsic or intrinsic religiosity, credibility, or rural cultural identity was associated with the one-item

measures of comprehension among the women who received either a definition, conventional metaphor, or cultural metaphor for randomization.

Research Question 7. The seventh research questions asked if a family or personal history of cancer increases comprehension of a randomization message. Among the women who received an explanation of randomization, a one-way ANOVA was performed on the comprehension items comparing women with no history of cancer, women who have a personal history of cancer, and women with a family history of cancer.

Research Question 8. The eighth research question asked if low-income, rural women's comprehension varies according to messages that use a conventional metaphor as compared to cultural metaphor or a definition. The research question was tested using a one-way ANCOVA with comprehension as the dependent variable, condition (definition, conventional metaphor, cultural metaphor) as the independent variable, and credibility as a covariate. The physiological data was analyzed using a mixed ANOVA with the BPM difference score (BPM-baseline) as the dependent variable, condition [targeted messages (definition and cultural metaphor conditions) versus conventional (metaphor condition)], time (18 seconds after stimulus), and the interaction of condition and time as the independent variables. Participant id number ($n=40$) was included as a random effect within condition.

Hypothesis 4. The fourth hypothesis predicted that comprehension of a message differs according to age. The hypothesis was tested using analysis of variance with comprehension as the outcome variable, and message strategy (control, definition,

conventional metaphor, cultural metaphor), age group (pre-retirement, post-retirement), and the interaction between the two as the predictors.

Research Question 9. The ninth research question asked if rural cultural identity, perceived credibility, or religiosity is associated with a negative affective response to a randomization message. Pearson's correlations were used to assess these relationships.

Research Question 10. The tenth research question asked if a history of cancer influences negative affective responses to the randomization message. A one-way ANOVA was performed on the arousal scale comparing women with no history of cancer, women who have a personal history of cancer, and women with a family history of cancer.

Research Question 11. The eleventh research question asked if low-income rural women's affective responses to messages vary according to whether they use a conventional metaphor as compared to a cultural metaphor or a scientific definition. Message strategy (definition, conventional metaphor, cultural metaphor) served as the predictor in a one-way analysis of variance with negative affect as the outcome variable. The physiological data was analyzed using a mixed ANOVA with the SCL value score $[(SCL - \text{baseline}) / \text{baseline}]$ as the dependent variable and condition (definition versus metaphor), time (18 seconds after stimulus), and the interaction of condition and time as the independent variables. Arousal was expected to vary according to message type, would be indicated by a significant p value for the condition variable.

Research Question 12. The twelfth research question asked if rural cultural identity, perceived credibility, or religiosity is associated with yielding to the

randomization message. The associations among the variables were assessed using Pearson's correlations.

Research Question 13. The thirteenth research questions asked if a family or personal history of cancer influences yielding to a randomization message. A one-way ANOVA was performed on the yielding scale comparing women with no history of cancer, women who have a personal history of cancer, and women with a family history of cancer.

Research Question 14. The fourteenth research question asked if yielding varies by age. The hypothesis was tested using analysis of variance with yielding as the outcome variable, and message strategy (control, definition, conventional metaphor, cultural metaphor), age group (pre-retirement, post-retirement), and the interaction between the two as the predictors.

Research Question 15. The fifteenth research question asked if a message varies when comparing low-income rural women's yielding responses to messages that use conventional metaphors as compared to cultural metaphors or a scientific definition. The research question was analyzed using analysis of covariance with message strategy (definition, conventional metaphor, cultural metaphor) as the independent variable, yielding as the dependent variable, and perceived credibility, extrinsic religiosity, intrinsic religiosity, and attention serving as covariates.

Research Question 16. The sixteenth research question asked if rural cultural identity, perceived credibility, or religiosity is associated with intentions to participate in

clinical trials as the result of exposure to the randomization message. Pearson's correlations were used to determine the relationships among the variables.

Research Question 17. The seventeenth research question asked if intentions to participate in clinical trials vary when comparing low-income rural women's responses to messages that use conventional metaphors as compared to cultural metaphors or a scientific definition. The research question was analyzed using analysis of covariance where posttest behavioral intentions were the dependent variable, message strategy (definition, conventional metaphor, cultural metaphor) as the independent variable, and significant correlates of behavioral intentions as the covariates including pre-test behavioral intentions, rural cultural identity, perceived credibility, extrinsic religiosity, attention, and yielding.

Hypothesis 7. The seventh hypothesis predicted that intentions to participate in clinical trials differ according to age. An analysis of covariance tested this research question using age group (pre-retirement, post-retirement) as the independent variable, post-intervention behavioral intentions as the dependent variable, and pre-intervention behavioral intentions as the covariate.

Research Question 18. The eighteenth research questions asked if a family or personal history of cancer influences post-intervention behavioral intentions to participate in a clinical trial in response to a randomization message. A one-way ANOVA was performed on the post-intervention intentions scale comparing women with no history of cancer, women who have a personal history of cancer, and women with a family history of cancer.

Research Question 19. The nineteenth research questions asked if attention, comprehension, arousal, and yielding explain rural women's intentions to participate in cancer clinical trials. A hierarchical regression analyses was conducted on post-intervention behavioral intentions using pre-intervention behavioral intentions, attention, comprehension, arousal, yielding, and all two-way interactions as predictors entered sequentially into the model.

Chapter 3

RESULTS

The formative research and stimulus development contributed to a 4-message condition (definition, conventional metaphor, cultural metaphor, control) between subjects pretest-posttest laboratory study. Preliminary data analysis was conducted to test for effects of question ordering and a manipulation check. All analyses were conducted using the Statistical Package for the Social Sciences (SPSS).

Order effects

Two versions of the questionnaire were administered in order to permit an evaluation of whether the order in which participants' encountered questions influenced their responses. Two one-way ANOVAS were conducted using questionnaire version as the independent variable and items/scales that measured attention, comprehension, negative affect, yielding, behavioral intentions, intrinsic and extrinsic religiosity, and rural identity as the dependent variables. There were no significant differences between the two versions for any of the variables.

Hypothesis Tests

Hypothesis 1

The first hypothesis predicted that rural identity would be correlated with religiosity. A Pearson's correlation tested the association between the rural identity scale and the intrinsic and extrinsic religiosity scales. There was a significant positive relationship between rural identity and both religiosity scales, demonstrating the association between rural identification and extrinsic religiosity, $r(106)=.30, p<.01$ and

intrinsic religiosity, $r(106)=.25, p<.05$. In addition, intrinsic and extrinsic religiosity were significantly correlated with one another, $r(106)=.61, p<.001$.

Hypothesis 2

The second hypothesis predicted that rural identity would be positively correlated with the perceived credibility of a message source. A Pearson's correlation tested the association between the rural identity scale and the perceived credibility scale. There was a significant positive relationship between rural identity and perceived credibility, $r(106)=.26, p<.01$.

Research Question 4

Research question four asked if rural cultural identity, perceived credibility, or religiosity is associated with attention to randomization messages. A Pearson's correlation tested the associations among rural identity, perceived credibility, and the intrinsic and extrinsic religiosity scales with the attention. Attention was significantly associated with intrinsic religiosity, $r(106)=.26, p<.01$, extrinsic religiosity, $r(106)=.37, p<.001$, and perceived credibility, $r(106)=.53, p<.001$. Attention was not significantly correlated with rural cultural identity, $r(106)=.15, p=.13$.

Research Question 5

The fifth research question asked if low-income, rural women's attention to a randomization message varies as a function of messages that use conventional metaphors as compared to cultural metaphors or a scientific definition. The research question was tested using analysis of variance with attention as the outcome variable, message strategy (control, definition, conventional metaphor, cultural metaphor) as the predictor, and

intrinsic religiosity, extrinsic religiosity, perceived credibility, and pre-intervention behavioral intentions as covariates. The analysis of variance was significant, $F(7,105) = 7.70, p < .001, R^2 = .36$, with perceived credibility and pre-intervention intentions explaining the largest proportion of the variance. There were no significant differences in attention among the message strategy conditions (see Table 3.1).

Table 3.1

Means and Standard Deviations for Attention by Condition

<u>Message Strategy</u>	Attention	
	<u>M</u>	<u>SD</u>
Control	4.19	.56
Definition	4.16	.44
Conventional Metaphor	4.16	.59
Cultural Metaphor	4.17	.39

Hypothesis 3

The third hypothesis predicted that attention to a randomization message would differ according to age. The hypothesis was tested using analysis of variance with attention as the outcome variable, and message strategy (control, definition, conventional metaphor, cultural metaphor), age group (pre-retirement, post-retirement), and the interaction between the two as the predictors. The results were not significant, $F(7,105) = .33, p = .94, R^2 = .02$ (see Table 3.2).

Table 3.2

Means and Standard Deviations for Attention by Condition and Age Group

<u>Message Strategy</u>	Attention	
	<u>M</u>	<u>SD</u>
Control		
Pre-retirement	4.28	.67
Post-retirement	4.14	.51
Definition		
Pre-retirement	4.17	.43
Post-retirement	4.15	.47
Conventional Metaphor		
Pre-retirement	4.11	.74
Post-retirement	4.19	.48
Cultural Metaphor		
Pre-retirement	4.31	.43
Post-retirement	4.22	.44

Hypothesis 4

The fourth hypothesis predicted that a history of cancer would increase attention to a randomization message. A one-way ANOVA was performed on attention comparing women with no history of cancer ($n=14$), women who have a personal history of cancer ($n=20$), and women with a family history of cancer ($n=72$). There were no significant differences in attention among the three groups, $F(2, 105)=.74$, $p=.48$, $R^2=.01$ (see Table 3.3).

Table 3.3

Means and Standard Deviations for Attention by Cancer History

<u>Cancer History</u>	Attention	
	<u>M</u>	<u>SD</u>
No history (n=14)	4.07	.51
Personal history (n=20)	4.10	.38
Family history (n=72)	4.21	.51

Research Question 6

The sixth research questions asked if rural cultural identity, perceived credibility, or religiosity is associated with comprehension of a randomization message. A Pearson's correlation was used to determine if extrinsic or intrinsic religiosity, credibility, or rural cultural identity was associated with the one-item measures of comprehension among the women who received either a definition, conventional metaphor, or cultural metaphor for randomization ($n=79$). Perceiving flipping a coin as a form of gambling was not significantly correlated with intrinsic religiosity, $r(79)=-.20$, $p=.08$, extrinsic religiosity, $r(79)=-.05$, $p=.65$, rural cultural identity, $r(79)=-.03$, $p=.79$, or perceived credibility, $r(79)=.06$, $p=.61$.

Research Question 7

The seventh research questions asked if a family or personal history of cancer increases comprehension of a randomization message. Among the women who received

an explanation of randomization, a one-way ANOVA was performed on the comprehension items comparing women with no history of cancer ($n=9$), women who have a personal history of cancer ($n=15$), and women with a family history of cancer ($n=58$). There were no significant differences in comprehension among the three groups, $F(78)=1.56, p=.22$ (see Table 3.4).

Table 3.4

Means and Standard Deviations for Comprehension by Cancer History

<u>Cancer History</u>	Comprehension	
	<u>M</u>	<u>SD</u>
No history (n=14)	3.64	.84
Personal history (n=20)	3.35	1.09
Family history (n=72)	3.65	1.00

Research Question 8

The eighth research question asked if low-income, rural women's comprehension varies according to messages that use a conventional metaphor as compared to cultural metaphor or a definition. The research question was tested using a one-way ANCOVA with comprehension as the dependent variable, condition (definition, conventional metaphor, cultural metaphor) as the independent variable, and credibility as a covariate. The results were non-significant, $F(5,78)=1.62, p=.17$ (see Table 3.5).

The physiological data provided some support that metaphors are associated with greater comprehension than a definition. A mixed ANOVA was conducted using the

BPM difference score (BPM-baseline) as the dependent variable, condition [targeted messages (definition and cultural metaphor conditions) versus standard (metaphor condition)], time (18 seconds after stimulus), and the interaction of condition and time as the independent variables. Significant differences were detected for condition, $F(1, 40)=4.62, p<.05$. Adjusted means and standard error estimates for the conventional messages and targeted messages were, respectively, .95(.42) and -.20(.31), indicating an increase in heart rate for the conventional metaphor condition, and a decrease in the targeted message conditions (see Figure 3.1). There was also a significant interaction of condition and time, $F(1, 709^9)=6.00, p<.05$, indicating that the stimuli influenced the variability in heart rate across time.

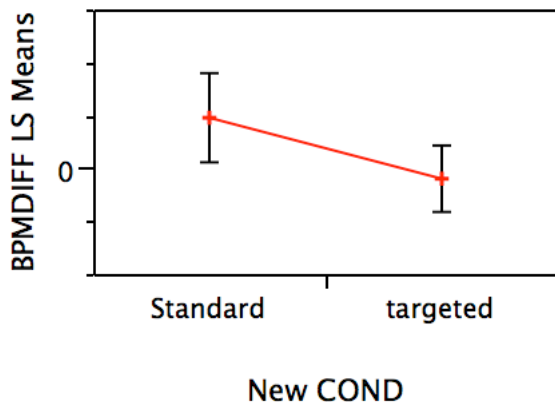
Table 3.5

Means and Standard Deviations for Comprehension by Condition

<u>Message Strategy</u>	Comprehension	
	<u>M</u>	<u>SD</u>
Control	3.63	.97
Definition	3.69	.89
Conventional Metaphor	3.32	1.29
Cultural Metaphor	3.68	.86

⁹ There were eighteen data points for each of the 40 participants; however, eleven data points were deemed extreme outliers and subsequently eliminated from the analysis.

Figure 3.1 Means Plot of the BPM Difference by Condition*



* Standard=conventional (coin flip) metaphor condition; Targeted= definition and cultural (sex of a baby) metaphor conditions.

Hypothesis 5

The fifth hypothesis predicted that comprehension of a message differs according to age. The hypothesis was tested using analysis of variance with comprehension as the outcome variable, and message strategy (control, definition, conventional metaphor, cultural metaphor), age group (pre-retirement, post-retirement), and the interaction between the two as the predictors. The hypothesis was not supported as there were no significant differences in comprehension between post-retirement women, $F(7,105) = .75$, $p = .64$, $R^2 = .05$ (see Table 3.6).

Table 3.6

Means and Standard Deviations for Comprehension by Condition and Age Group

<u>Message Strategy</u>	Comprehension	
	<u>M</u>	<u>SD</u>
Control		
Pre-retirement	3.44	1.13
Post-retirement	3.72	.89
Definition		
Pre-retirement	3.56	1.03
Post-retirement	3.85	.69
Conventional Metaphor		
Pre-retirement	3.00	1.50
Post-retirement	3.54	1.13
Cultural Metaphor		
Pre-retirement	3.54	.97
Post-retirement	3.80	.77

Research Question 9

The ninth research question asked if rural cultural identity, perceived credibility, or religiosity is associated with a negative affective response to a randomization message. The results of Pearson's correlations using the sample of women who received an explanation of randomization and reported that they remembered randomization being mentioned in the video ($n=67$) demonstrated that neither rural cultural identity, $r(67)=-.03$, $p=.80$, perceived credibility, $r(67)=-.14$, $p=.27$, intrinsic religiosity, $r(67)=.02$, $p=.88$,

nor extrinsic religiosity, $r(67)=.10$, $p=.38$ were significantly correlated with negative affective response to the randomization message.

Research Question 10

The tenth research question asked if a history of cancer influences negative affective responses to the randomization message. A one-way ANOVA was performed on the arousal scale comparing women with no history of cancer ($n=9$), women who have a personal history of cancer ($n=15$), and women with a family history of cancer ($n=58$). There were no significant differences in arousal among the three groups, $F(2, 66)=.34$, $p=.71$ (see Table 3.7).

Table 3.7

Means and Standard Deviations for Arousal by Cancer History

<u>Cancer History</u>	Arousal	
	<u>M</u>	<u>SD</u>
No history	2.44	.85
Personal history	2.40	.67
Family history	2.36	.78

Research Question 11

The eleventh research question asked if low-income rural women's affective responses to messages vary according to whether they use a conventional metaphor as compared to a cultural metaphor or a scientific definition. Message strategy (definition,

conventional metaphor, cultural metaphor) served as the predictor in a one-way analysis of variance with negative affect as the outcome variable. There were no significant differences among the three groups, $F(2, 66)=.48, p=.62$. An examination of the mean arousal for each condition indicated that the cultural metaphor condition was slightly higher than the conventional metaphor and the definition (See Table 3.8).

Analysis of the physiological data also did not support the hypothesis. A mixed ANOVA was conducted using the SCL value score $[(SCL\text{-baseline})/baseline]$ as the dependent variable and condition (definition versus metaphor), time (18 seconds after stimulus), and the interaction of condition and time as the independent variables. Arousal was expected to vary according to message type, would be indicated by a significant p value for the condition variable. The hypothesis that arousal would vary by message type ([targeted (definition and cultural metaphor conditions) versus standard (conventional metaphor)]) was not supported by the physiological measures. Although condition and the interaction of condition and time were not significant predictors, data revealed a main effect for time, $F(1, 831)^{10}=52.20, p<.001$, such that arousal was highest immediately following the stimulus in all conditions, followed by decay.

Research Question 12

The twelfth research question asked if rural cultural identity, perceived credibility, or religiosity is associated with yielding to the randomization message. The results of Pearson's correlations demonstrated that self-reported yielding was not significantly correlated with rural cultural identity, $r(67)=.09, p=.47$, but it was

¹⁰ The degrees of freedom are based on eighteen observations each for the 47 participants included in the analysis. Fifteen observations were eliminated due to out of range values.

significantly positively correlated with perceived credibility, $r(67)=.36, p<.01$, intrinsic religiosity, $r(67)=.33, p<.01$, and extrinsic religiosity, $r(67)=.27, p<.05$.

Table 3.8

Means and Standard Deviations for Arousal by Condition

<u>Message Strategy</u>	Arousal	
	<u>M</u>	<u>SD</u>
Control	2.75	.87
Definition	2.23	.73
Conventional Metaphor	2.22	.87
Cultural Metaphor	2.41	.56

Research Question 13

The thirteenth research questions asked if a family or personal history of cancer influences yielding to a randomization message. A one-way ANOVA was performed on the yielding scale comparing women with no history of cancer ($n=9$), women who have a personal history of cancer ($n=15$), and women with a family history of cancer ($n=58$). There were no significant differences in yielding among the three groups, $F(2, 81)=.06, p=.94$ (see Table 3.9).

Research Question 14

The fourteenth research question asked if yielding varies by age. The research question was tested using analysis of variance with yielding as the outcome variable, and

message strategy (control, definition, conventional metaphor, cultural metaphor), age group (pre-retirement, post-retirement), and the interaction between the two as the predictors. The model was not significant, $F(7,105) = .62, p = .74, R^2 = .06$ (see Table 3.10).

Table 3.9

Means and Standard Deviations for Yielding by Cancer History

<u>Cancer History</u>	Yielding	
	<u>M</u>	<u>SD</u>
No history	3.83	.71
Personal history	3.93	.42
Family history	3.99	.70

Research Question 15

The fifteenth research question asked if a message varies when comparing low-income rural women's yielding responses to messages that use conventional metaphors as compared to cultural metaphors or a scientific definition. The research question was analyzed using analysis of covariance with message strategy (definition, conventional metaphor, cultural metaphor) as the independent variable, yielding as the dependent variable, and perceived credibility, extrinsic religiosity, intrinsic religiosity, and attention serving as covariates. The overall model was significant, $F(6, 66) = 4.93, p < .001, R^2 = .33$, but message strategy was not a significant predictor (see Table 3.11).

Table 3.10

Means and Standard Deviations for Yielding by Condition and Age Group

<u>Message Strategy</u>	Yielding	
	<u>M</u>	<u>SD</u>
Control		
Pre-retirement	4.10	.74
Post-retirement	4.25	.49
Definition		
Pre-retirement	3.83	.79
Post-retirement	3.94	.17
Conventional Metaphor		
Pre-retirement	4.17	1.00
Post-retirement	3.85	.82
Cultural Metaphor		
Pre-retirement	3.82	.56
Post-retirement	3.92	.45

Research Question 16

The sixteenth research question asked if rural cultural identity, perceived credibility, or religiosity is associated with intentions to participate in clinical trials as the result of exposure to the randomization message. The results of Pearson's correlations demonstrated that rural cultural identity and perceived credibility was significantly positively correlated with both pre-intervention behavioral intentions to participate in clinical trials (rural cultural identity: $r(79)=.28, p<.05$; perceived credibility $r(79)=.37,$

$p < .001$), and post-intervention behavioral intentions to participate in clinical trials (rural cultural identity: $r(79) = .29, p < .05$; perceived credibility $r(79) = .49, p < .001$). Intrinsic religiosity was significantly positively correlated with post-intervention behavioral intentions, $r(79) = .23, p < .05$, but not pre-intervention behavioral intentions, $r(79) = .19, p = .09$. Extrinsic religiosity was not significantly correlated with pre-intervention behavioral intentions, $r(79) = .16, p = .17$, or post-intervention behavioral intentions to participate in clinical trials, $r(79) = .17, p = .13$.

Table 3.11

Means and Standard Deviations for Yielding by Condition

<u>Message Strategy</u>	Yielding	
	<u>M</u>	<u>SD</u>
Control	4.21	.54
Definition	3.90	.66
Conventional Metaphor	4.00	.91
Cultural Metaphor	3.88	.54

Research Question 17

The seventeenth research question asked if intentions to participate in clinical trials vary when comparing low-income rural women's responses to messages that use conventional metaphors as compared to cultural metaphors or a scientific definition. The research question was analyzed using analysis of covariance where posttest behavioral

intentions were the dependent variable, message strategy (definition, conventional metaphor, cultural metaphor) as the independent variable, and significant correlates of behavioral intentions as the covariates including pre-test behavioral intentions, rural cultural identity, perceived credibility, extrinsic religiosity, attention, and yielding. The overall model was significant, $F(9,67)=20.95, p<.001, R^2=.77$ as a result of the significant pretest behavioral intentions and yielding covariates (pretest behavioral intentions: $F(1,67)=107.49, p<.001$; yielding: $F(1,67)=4.44, p<.04$). Message strategy was not a significant predictor of behavioral intentions (see Table 3.12).

Table 3.12

Means and Standard Deviations for Behavioral Intentions by Condition

<u>Message Strategy</u>	Behavioral Intentions	
	<u>M</u>	<u>SD</u>
Control	3.98	.88
Definition	3.80	.66
Conventional Metaphor	3.95	1.00
Cultural Metaphor	3.60	.82

Hypothesis 7

The seventh hypothesis predicted that intentions to participate in clinical trials differ according to age. An analysis of covariance tested this research question using age group (pre-retirement, post-retirement), message strategy, and the interaction of the two

as the independent variables, post-intervention behavioral intentions as the dependent variable, and pre-intervention behavioral intentions as the covariate. The model was significant, $F(8, 105)=24.26, p<.001$, largely due to the pre-intervention behavioral intentions covariate, $F(1, 105)=172.58, p<.001$. There were no significant differences with regard to behavioral intentions to participate in a clinical trial among the two age groups, $F(1, 105)=3.13, p=.08$ (see Table 3.13).

Table 3.13

Means and Standard Deviations for Post-Intervention Behavioral Intentions
by Condition and Age Group

<u>Message Strategy</u>	Behavioral Intentions	
	<u>M</u>	<u>SD</u>
Control		
Pre-retirement	3.69	1.01
Post-retirement	4.00	.59
Definition		
Pre-retirement	3.81	.73
Post-retirement	3.79	.35
Conventional Metaphor		
Pre-retirement	4.06	1.07
Post-retirement	3.85	.83
Cultural Metaphor		
Pre-retirement	3.04	.58
Post-retirement	3.42	.81

Research Question 18

The eighteenth research questions asked if a family or personal history of cancer influences post-intervention behavioral intentions to participate in a clinical trial in response to a randomization message. A one-way ANOVA was performed on the post-intervention intentions scale comparing women with no history of cancer ($n=14$), women who have a personal history of cancer ($n=20$), and women with a family history of cancer ($n=72$). There were no significant differences in behavioral intentions among the three groups, $F(3, 105)=60.47, p<.001$. It is interesting to note that women who had a family history of cancer ($M=3.86, SD=.82$) reported the highest mean level of intentions, followed by women with a personal history of cancer ($M=3.75, SD=.60$), and women with no history of cancer ($M=3.75, SD=.52$).

Table 3.14

Means and Standard Deviations for Post-Intervention

Behavioral Intentions by Cancer History

<u>Cancer History</u>	Behavioral Intentions	
	<u>M</u>	<u>SD</u>
No history	3.75	.52
Personal history	3.75	.60
Family history	3.86	.82

Research Question 19

The nineteenth research questions asked if attention, comprehension, arousal, and yielding explain rural women's intentions to participate in cancer clinical trials. A hierarchical multiple regression analyses was conducted to assess the influence of age, religiosity, cultural identity, pre-intervention intentions, as well as the independent and moderating efforts of attention, comprehension, arousal, and yielding on post-intervention behavioral intentions. Participant traits that were expected to be associated with behavioral intentions, including age, intrinsic religiosity, and rural cultural identity was entered on the first step. Pre-intervention intentions were considered a predisposing factor for post-intervention intentions and were entered at the second step. Message strategy was entered on the third step, with the scientific definition and conventional metaphor conditions collapsed and coded as 0 to compare to the cultural metaphor condition. McGuire's information processing measures, including attention, comprehension, arousal, yielding, and credibility were entered on the fourth step. The interactions of message strategy with each of the message processing variables were included on the fifth step. All two-way interactions among the message processing variables were entered on the sixth and final step.

The full regression model (see Table 3.15) was significant [$F(26,80)=17.10$, $p<.001$]. In order to create a more parsimonious model, variables that did not significantly contribute to the variance in behavioral intentions were removed (see Table 3.16). The analyses revealed that among participant traits, women who reported a stronger rural cultural identity were more likely to intend to participate in clinical trials

[$F(1,81)=10.13, p<.05, R^2=.11$]. As was anticipated, pre-intervention intentions to participate in clinical trials was highly predictive of post-intervention intentions [$F(2,81)=96.90, p<.001, R^2 \text{ change}=.60$]. Contrary to what was predicted, message strategy did not reveal a main effect on posttest behavioral intentions, but did interact significantly with attention [$F(9,81)=35.86, p<.001, R^2 \text{ change}=.04$]. The disordinal interaction indicates that while lower levels of attention yield higher levels of change in behavioral intentions for women who receive the cultural metaphor, moderate to high levels achieve like changes for both cultural metaphors, conventional metaphors, and scientific definitions. At the highest levels of attention, however, the conventional and scientific metaphor reveal a pattern that is the reverse of the lowest levels, such that greater changes in behavioral intentions occur in the group receiving the conventional or scientific definition (see Figure 3.2). This interaction suggests that women need to afford more attention to traditional messages in order to be influenced to the same degree as messages containing a cultural metaphor.

There were three significant interactions among the message processing variables [$F(13, 81)=24.48, p<.001, R^2 \text{ change}=.02$]. First, there was a significant interaction between attention and arousal. Specifically, at lower levels of attention, increased arousal was positively related to intentions to participate in clinical trials. At higher levels of attention, increased arousal was negatively related to intentions to participate in clinical trials. Second, there were significant interactions between comprehension and both yielding and credibility arousal. The interaction between comprehension and yielding was such that participants who perceived the flip of a coin as a form of gambling were

more likely to report intentions to participate in clinical trials if they judged the message to be persuasive. The interaction of comprehension and credibility was similar in that when agreement that flipping a coin was a form of gambling was low, those who perceived the message source as being higher in credibility were more likely to intend to participate in trials than participants who perceived the message source as being lower in credibility. Taken together, when comprehension was low, perceiving the source as credible was positively related to intentions. When comprehension was high, perceiving the message as persuasive was positively related to intentions.

Table 3.15

Full Regression Model Predicting Post-Intervention Behavioral Intentions

Predictor Variables	β	R^2	R^2 change	F-change
Step 1: Trait variables		.18		3.18
Age	-.01			
Education	.02			
Rural identity	.32***			
Intrinsic religiosity	.09			
Extrinsic religiosity	.12			
Step 2: Pre-disposing variables		.73	.56	153.54
Pre-intervention intention	.83****			
Step 3: Message Strategy (MS)		.73	.00	.02
Cultural metaphor ^a	.01			
Step 4: Message processing (MP)		.79	.06	4.14
Attention	.21			
Comprehension	-.08*			
Arousal	-.17			
Yielding	.16*			
Credibility	.26			
Step 5: MS & MP interactions		.84	.04	3.07
Attention x MS	-.91***			
Comprehension x MS	.03			
Arousal x MS	-.15			
Yielding x MS	-.13			
Credibility x MS	.22			
Step 6: MP interactions		.89	.05	3.10
Attention x Comprehension	.10			
Attention x Arousal	-.35***			
Attention x Yielding	-.17			
Attention x Credibility	.29			
Comprehension x Arousal	.06			
Comprehension x Yielding	.15***			
Comprehension x Credibility	-.46***			
Arousal x Yielding	-.10			
Yielding x Credibility	-.01			

Full model: $F(26,80) = 17.10, p < .001$; * $p < .10$, ** $p < .05$, *** $p < .01$, **** $p < .001$; β = Unstandardized regression coefficients.

^a Cultural metaphor condition coded as 1.

Table 3.16

Reduced Regression Model Predicting Post-Intervention Behavioral Intentions

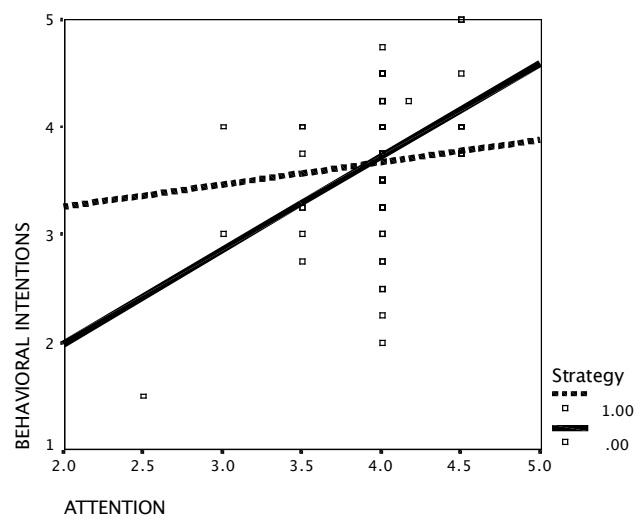
Predictor Variables	β	R^2	R^2 change	F-change
Step 1: Trait variables		.11		10.13***
Rural identity	.33***			
Step 2: Pre-disposing variables		.71	.60	163.14****
Pre-intervention intention	.84****			
Step 3: Message Strategy (MS)		.71	.00	.004
Cultural metaphor ^a	.007			
Step 4: Message processing (MP)		.78	.07	4.74***
Attention	.20			
Comprehension	-.09**			
Arousal	-.06			
Yielding	.17**			
Credibility	.20			
Step 5: MS & MP interactions		.82	.04	14.30****
Attention x MS	-.85****			
Step 6: MP interactions		.81	.02	2.39***
Attention x Arousal	-.24			
Comprehension x Yielding	.12*			
Comprehension x Credibility	-.23*			

Final model: $F(13,81) = 27.48, p < .001$; * $p < .10$, ** $p < .05$, *** $p < .01$, **** $p < .001$; β = Unstandardized regression coefficients.

^a Cultural metaphor condition coded as 1.

Figure 3.2

Interaction of Attention and Message Strategy: Predicting Behavioral Intentions to Participate in Clinical Trials*



0=control, definition, conventional metaphor; 1=cultural metaphor

Chapter 4

DISCUSSION

Reducing inequities in health is an important goal of many health communication campaigns. Pursuing this goal requires understanding that inequities are perpetuated through communicative practices that consciously or unconsciously reflect stereotypes and prejudicial attitudes (Hecht, 1998). Thus, interaction must be closely examined in various health contexts to identify where and when language is contributing to differential health outcomes for underserved populations. In some cases, even well-intentioned attempts to make information more understandable may actually serve to reinforce disparities. Metaphorical language, for example, is a common technique used by health care providers to translate complex or scientific aspects of medical care into lay language. In some cases, however, metaphors may have unanticipated meanings for audiences whose cultural background differs from the message creator.

The purpose of this study was to investigate the outcomes of metaphor use for communication about randomization in the context of clinical trials within a medically underserved audience of rural, low-income, older adult women. A variety of methods were used in this study in order to further understanding on how metaphors are perceived and how they might influence (positively or negatively) the cancer treatment decisions of rural women. Formative research was conducted to solicit the opinions of the intended audience regarding clinical research in general, the concept of randomization, and reactions to metaphorical explanations of randomized assignment to condition in a clinical trial. Based on the formative research, three stimulus messages were designed to

determine the effects of specific strategies for explaining randomization on message outcomes. An experimental study was designed around the stimulus videos to study outcomes associated with each type of message strategy. The specific outcomes of interest were largely drawn from McGuire's model of information processing (1972), including attention, comprehension, affective response, yielding (perceived persuasiveness), and behavioral intentions regarding clinical trials.

The overall goals of this research project were to advance theoretical knowledge in the area of strategic health message design in three important ways. First, this study introduced and explored regional identity as an audience segmentation construct for health messages. Second, it empirically tested the outcomes of three different message strategies (definition, metaphor, and culturally-specific metaphor) for use with medically underserved audiences. Third, it examined whether McGuire's model of behavior change is an appropriate framework for understanding intentions to participate in cancer clinical trials among a rural, low-income audience. The following section will elaborate on the implications of this research for each of these three areas.

Implications of Rural Identity for Health Communication

Current approaches to rural health define "rurality" according to population density and proximity to urban areas, with far too little emphasis placed on the larger cultural factors that shape attitudes and behaviors about health (Scheer, et al., 2000). Thus, the first goal of this study was explore regional identity as an audience segmentation construct for health messages. Scholars such as Barbara Ching (2001; Ching & Creed, 1997) have cogently argued that geographic isolation (actual or

perceived) cultivates a culture with distinct ideals. Ching claims, for example, that rural audiences are likely to value practical knowledge over educational or social “sophistication”. To date, it has been difficult to examine the potential influence of rural identity on health outcomes due to a lack of quantitative measures of this construct.

This dissertation constituted an initial effort in empirically measuring rural identity and determining what influences it may have on health. Due to the lack of measurement instruments available in the literature, a scale was adapted to provide an initial measurement of the degree to which people identified themselves as rural Pennsylvanians. In addition to demonstrating considerable face validity, the scale can also be argued to have a good degree of content validity because it contained items that corresponded to the content domains (e.g., group pride and belonging) of other established identity scales (e.g., Phinney’s (1992) Multigroup Ethnic Identity Measure).

The scale also has a degree of convergent validity. Qualitative work in the rural health literature identifies faith and religion as commonly being integral to the experience of illness in rural communities. Thus, the first prediction in this study was that rural identity would be positively related to self-reported intrinsic and extrinsic religiosity. The hypothesis was supported, providing evidence in support of both the validity of the rural identity scale and the idea that religiosity is likely an important component of rural identity. The religious component of rural identity may be interpreted as a very positive finding for people interested in promoting health in rural areas. For example, a high degree of intrinsic religiosity, such as believing in God and prayer, may help an individual have an increased sense of efficacy when dealing with a difficult diagnosis or a

prolonged course of treatment. Extrinsic religiosity may translate into possessing a social network able to provide the required instrumental, informational, or emotional social support for people to maintain good health (House, 1981). At the same time, faith and religion may provide new and unique challenges to care. For example, a woman might have concerns that pursuing a given treatment might indicate a lack of faith in God for healing.

Another interesting finding associated with rural identity was that it was positively related to perceived credibility of a physician. Thus, women who identified more strongly with being rural were also more likely to rate physician who served as the message source in the stimulus messages as being credible. It is important to reiterate that there was an overt statement in the videos in which the physician identified himself as a family physician in rural central Pennsylvania. The positive correlation between rural identity and credibility suggests that there may be both positive and negative stereotypes of rurality and that these stereotypes may play out in similar ways as the positive and negative stereotypes of aging that have been articulated by Hummert and colleagues (Hummert, 1994a; Hummert, 1994b; Hummer, Garstka, & Shaner, 1995). For women who did not strongly identify as being rural, the physician's statement may have activated negative social stereotypes about rurality such as being backward and behind the times. Conversely, the same statement may have activated positive stereotypes of rurality such as authenticity and an ethic of care for women who strongly identified as being rural.

Given that credibility is key component of any type of health message, rural identity may be an important audience characteristic that is currently being underutilized

in both interpersonal and health campaign messages. The implications for the physician-patient relationship may be that important and/or difficult health information may be best communicated to women with strong rural identities by a family physician whom the patient trusts. For example, women who are considering participating in a cancer clinical trial may find it easier to ask her family physician pertinent questions about the particular treatment rather than the specialist who recommended it. A potential problem with encouraging greater participation of rural family physicians in the cancer treatment decisions of their patients is it could introduce another set of attitudinal or practical barriers (Siminoff, Zhang, Colabianchi, Sturm, & Shen, 2000). Thus, the ideal for improving rural healthcare is to improve continuing education practices of rural physicians and provide patients the opportunity to consult with their family physician about their treatment options if they so choose.

The implications for health campaigns targeted at rural health are similar. Health messages designed for the general population generally employ sources that are perceived as having a high level of subject expertise. For rural populations, medical knowledge is likely not a sufficient criteria for gaining the trust of a rural audience. In addition, it may be important for rural audiences to perceive a sense of similarity to the message source. Thus, messages designed for rural women with strong rural identities are likely to benefit from explicit statements that reflect a shared rural identity. The possibility of using rural identity as an audience segmentation tool for health messages is not without potential problems. For women living in rural areas who do not have a strong rural identity, messages utilizing appeals to rural identity may be perceived as less

credible by these audiences. Thus, messages using identity as a segmentation strategy would have to be carefully disseminated.

A Cultural Perspective on Health Metaphor

The second goal of this study was to expand on previous persuasion research on the effectiveness of metaphor by investigating whether there are cultural differences in the way a metaphor is perceived as evidenced by differential message outcomes. Social influence perspectives such as the superior organization view of metaphor hold that metaphors are effective persuasion tools. As such, metaphors are often used to communicate health information on a range of topics, including cancer clinical trials. Cultural theorists contend, however, that metaphor as a persuasion tool warrants investigation in every population in which it used. They argue that the use and interpretation of metaphor requires extensive cultural knowledge and thus increases the potential for ineffective and potentially inappropriate communication (e.g., Quinn, 1991).

Drawing on this work, this study hypothesized that the semantic associations evoked by a metaphorical language would have an affective component. It was reasoned that a culturally-appropriate metaphor (i.e., sex of a baby) would be associated with weaker negative affective responses than a culturally-inappropriate metaphor (i.e., flip of a coin). Furthermore, it was thought that more negative affective responses would be associated with less desirable message outcomes, such as paying less attention to the message, reduced comprehension of the message, and lower intentions to participate in cancer clinical trials.

The results of the formative research were consistent with this reasoning. The women nearly unanimously reported that they would be strongly opposed to the conventional metaphor (e.g., flip of a coin) used in this study as well as similar types of what they referred to as “gambling” metaphors. Although participants in the interviews and focus groups felt that they would react negatively to conventional metaphors being used in a medical situation, the data from the laboratory study suggests otherwise. It was expected that the type of metaphor, or message strategy, used to convey a description of randomization would influence how much attention people paid to the message, how they comprehended the message, how aroused they were by the message, how much they would yield to the message, and the degree to which they would report intentions to participate in cancer clinical trials.

The ANOVAs produced no significant differences among the conditions with respect to these outcomes. However, the regression model revealed a significant interaction for condition and attention as predictor of behavioral intentions. The nature of this relationship was such that when women who allocated limited attention to a cultural metaphor were influenced to a similar degree as women who paid more attention and received a definition or conventional metaphor. There were no message effects at modest levels of attention, and conventional messages appear to be more influential than the cultural message at the very highest attention levels. This finding suggests that the benefits of culturally sensitive messages will be most clearly observed when patients have limited cognitive resources to devote to message processing. There are many potential reasons why a patient might not attend to a particular message, not the least of

which is coping with a cancer diagnosis. For this reason, clinical trial recruitment efforts are likely to benefit from utilizing culturally sensitive messages to explain randomization.

Models for Rural Health Behavior Change

The third goal of this study was to examine whether McGuire's model of behavior change can predict intentions to participate in cancer clinical trials among rural, low-income, older adult women. McGuire's information processing paradigm, which posits that behavior change is the sixth step in a consecutive series of health promotion goals. Each goal must be attained in order to effect change in behavior or behavioral attentions. Thus, this study investigated the degree to which message strategy, age, and cancer history influenced outcomes as specified in the model.

The first outcome in the model is attention. In this project, attention was positively associated with intrinsic and extrinsic religiosity and credibility. In other words, participants who were more religious and perceived the message source to be more credible were more likely to pay attention. The latter finding is consistent with the communication literature on source credibility, but the former is a little less intuitive. One explanation for this result is that religion serves as a health information gatekeeper. Parrott and colleagues (2004) demonstrated that religion influences exposure to media messages, which in turn affects exposure to information about health and science. In a similar vein, the research reviewed earlier described how health plays a prominent feature in religious services through the practices of prayer, anointing, and personal testimony (Horton, 1984; Simpson & King, 1999). Thus, religion appears to have an important influence on if people are exposed to health information and how the information is

transmitted. For example, members of conservative Christian churches may talk freely about all aspects of certain cancers such as leukemia or brain cancers, but deem discussion of others (e.g., breast or testicular cancers) taboo. Applied to this study, religious participants may have been more likely to pay attention to the randomization message because they had been previously exposed to information about clinical trials through someone in their network, or they perceived that the information might benefit someone in their social network in the future.

A second potential explanation may have been that the video produced by the National Cancer Institute contained two specific instances where clinical trials were encouraged because of the opportunity to help others and the opportunity to be “unselfish” (See Appendix F). Although these two statements are not strictly religious in nature, they do resonate with Biblical concepts. It is possible that people with religious affiliations may have put more effort into understanding the message because of the combination of having the religiosity questions as a prime, followed by message excerpts that are consistent with their religious beliefs. A third explanation is that people who are highly religious may be more susceptible to social desirability factors than other participants. For example, if a participant perceived herself as being “a good Christian”, she likely reported being highly religious. Even if a woman had difficulty paying attention to the video, it is possible that reporting those difficulties (i.e., not paying attention to a video you were paid to watch) may have been inconsistent with religious values such as honesty.

Interestingly, attention was not found to differ according to rural identity, age, or cancer history. It is possible that the lack of findings can be attributed to the marginal reliability of the attention measure. An alternative explanation is that the relationship between rural identity and attention is indirect, however, the available sample size in this study was a barrier to creating models where that possibility could be further explored.

Knowledge and comprehension were among the most difficult items to measure in this study, despite the fact that the knowledge scales consisted of items that have been used in previous studies. One explanation for the measurement problems in this research derives observations recorded by the research assistants that described participants as making a concerted effort to be consistent with their pretest and posttest responses. Often, participants would make comments after viewing the video suggesting that the material was “interesting” or that they “learned a lot.” However, when these participants were asked questions pertaining to the video content on the posttest questionnaire, they often said things like, “I can’t remember what I said before...I think it was (specific answer choice).”

It is possible that this population has heightened desire for consistency and perceived giving different answers to a similar set of questions within a short time period as inconsistent. Due to the older age of many of the participants, it is also possible that participants considered the questionnaires to be a memory test similar in nature to what they might experience in a physician’s office. If so, it would be despite numerous reassurances to participants that the questionnaires were not tests, and that their answers

to the questions should be based on their current understanding of the issues being asked about.

Due to these problems, the knowledge items were not ultimately included in the data analysis in favor of a subjective measure of how participant's comprehended the randomization message. Unfortunately, the comprehension measure did not fair any better than the knowledge measure with regard to detecting relationships with rural cultural identity, credibility, religiosity, cancer history, or age differences. Clearly, future research should work on validating measurement tools across population groups, including rural and older adult populations.

Although affect is not a component considered in McGuire's model, it was included in this study due to a number of studies in communication that demonstrate that affect is an important factor in how people process messages. Although the SOV of metaphor argues that metaphors will spark cognitive associations, it was predicted that metaphors would also have affective associations that would influence message outcomes. None of these relationships (rural identity, credibility, religiosity, cancer history, message strategy) were confirmed in this study. The lack of findings may have been related to the lack of variance in the affect scale. Also, this study focused exclusively on negative affect. This may have not adequately captured the diversity of emotions that participants experienced as part of this study. It was originally reasoned that messages about cancer would be inherently negative; however, this assumption was likely incorrect given that the mean level of negative affect in response to the messages was rather low.

One of the latter variables in McGuire's model is yielding (i.e., perceived persuasiveness) with a message. In this study, self-reported yielding was positively associated with perceptions of credibility and intrinsic and extrinsic religiosity. Thus, people who perceived the message source as credible and people who were highly religious were more likely to report agreeing with the message. If someone perceives a source to be credible, it is logically consistent that they would also agree with the source, especially on non-controversial topics where expertise is deemed important, such as medicine. As for religiosity, it is possible that people who are religious may be more receptive to figures of power or authority. Alternatively, they may have perceived the video to have religious overtones (i.e., helping other people) and were more likely to agree with information that they perceived as being consistent with their religious beliefs.

Yielding was not found to be associated with cultural identity or age. Although the lack of findings with regard to rural cultural identity are not able to help us further our understanding of rural identity and receptiveness to messages about clinical trials, the findings with regard to age are quite positive. Social stereotypes of older adults often lead to expectations that older people will either be overly passive to a physician's wishes or overly resistant to unfamiliar ideas. Neither response was demonstrated in this data.

Changing behavioral intentions is often the intended outcomes of health intervention campaigns. This research demonstrated that rural cultural identity was significantly positively correlated with both pre-intervention behavioral intentions to participate in clinical trials and a predictor of post-intervention behavioral intentions to participate in clinical trials. This finding is in line with previous studies that have found

rural populations to have positive attitudes toward participating in clinical trials. Religiosity was also significantly positively correlated with post-intervention behavioral intentions to participate in clinical trials but not pre-intervention behavioral intentions. This may provide further evidence of the content of the video produced by the National Cancer Institute being perceived as relevant in some way to religious values. Specifically, there was no association between religiosity and intentions to participate before the video, but there was an association after the stimulus. A potential explanation for this observed pattern is that religious participants interpreted the video message as saying that if someone did not participate in a clinical trial, it would be selfish and demonstrate a lack of willingness to help others.

Increasing age was negatively associated with behavioral intentions in this study, a finding that is consistent with some of the previous work on the influence of age on intentions to participate in clinical trials. However, there were no significant differences in age when participants were separated into cohorts. Future research may want to pursue how lifespan development influences health care decision making as people age.

It was hypothesized that having a personal or family history of cancer might predispose one to have a greater interest in participating in a cancer clinical trial, although there was no evidence of any such differences in the data. It seems logical that having experience with the disease either personally or through a family member would make a person evaluate treatment options differently. If this is in fact true, this data was not able to achieve the level of sensitivity necessary to detect these differences. More

research needs to be conducted on the process by which women with varying cancer histories evaluate and make decisions based on cancer clinical trials messages.

Contributions to Communication Theory

Given the complexity of this project and the large number of research questions and hypotheses that were previously discussed, this section will provide a brief summary of the overall contributions of this research study to the field of communication. Specifically, the findings will be reviewed with a focus on how this research advanced knowledge with regard to communicating about health in a way that is consistent with the cultural values of rural populations. The four main areas to be discussed include the development of a rural identity scale, correlates of rural identity, theoretical implications for the superior organization view of metaphor, and the theoretical implications for McGuire's model of information processing.

It has now been over a decade since scholars articulated the need for culture to play a larger role in health promotion (Airhihenbuwa, 1995; Parrott, Kahl, & Maibach, 1995). One of the challenges of incorporating culture in health communication efforts is identifying or defining culture (Faulkner, et al., 2006). In the case of rural health, an inability to measure or define rural culture has been a major impediment to the reduction of health disparities. The introduction of a scale that allows individuals to self-identify as rural has the potential to help health communicators do a better job of identifying and segmenting rural audiences. It affords the opportunity for future research an opportunity to investigate the degree to which self-identified rural populations correspond to national classification systems such as those used by the U.S. Bureau of the Census and the Office

of Management and Budget, as well as determine which type of measurement is more useful to understanding and reducing rural health disparities.

In addition to providing an initial measurement instrument, this study provides data on the correlates of rural identity among residents of central Pennsylvania. The finding that rural identity is correlated with extrinsic and intrinsic religiosity as well as source credibility provides some insights into the values of this group. Specifically, future research needs to focus on the specific ways religion and spirituality influences health decision-making within rural populations (Parrott, et al., 2004). It could be that religion and spirituality help explain what kinds health information rural residents are/ are not exposed to (e.g., talking about cancer as acceptable or taboo), where they receive the information (e.g., in church, newsletters from religious organizations), and how it is delivered (e.g., pulpit, prayer requests, interpersonal relationships).

The finding that credibility is related to rural identity has some interesting implications, too. Previous research on source credibility has found two main sources of credibility including 1) topic expertise and 2) trustworthiness (i.e., motivation to tell the truth) (Metzger, et al, 2003). A common way to establish trustworthiness with a medically underserved population is to utilize a message source that is demographically matched to the population in some way (e.g., racial/ethnic background, socioeconomic status) (Kreuter & McClure, 2004). Due to the lack of obvious physical characteristics that would denote “rurality”, the source in this study explicitly mentioned that he practiced medicine in rural Pennsylvania. The result was that rural identity was positively correlated with credibility. This extends previous research by suggesting that

demographic similarities may need to be explicitly mentioned to establish credibility for some audiences, and reinforcing the need for precise segmentation of the intended audiences for these messages to avoid cases in which audiences with a non-rural identity perceive a rural source to have reduced credibility.

The contributions of this study to the superior organization view of metaphor for understanding metaphorical messages are primarily related to the claims that metaphors elicit cognitive associations that influence attitudes about a particular topic. Applying this tenet of the theory to this study, it was hypothesized that cultural metaphors would elicit more positive associations than conventional metaphors and thus be more strongly associated with desired message outcomes. The direct influence of message strategy on message outcomes was not observed. However, the interaction of message strategy with attention suggests that under certain conditions (e.g., low attention), the cultural metaphor did have more positive associations and thus had a greater persuasive effect than conventional strategies.

Finally, this research has two interesting contributions regarding the utilization of McGuire's model of information processing for rural populations. The first contribution is in the area of measurement and research design. The ability to use theory to guide health interventions is only useful to the degree that it can be evaluated. In order to evaluate the usefulness of a theory, it is important to have valid and reliable measures. The measurement problems that were experienced in this study, particularly related to knowledge, point to the necessity of evaluating measures and research methods using diverse samples. It is possible that the measures of knowledge used in this study did not

address salient issues for this population, or that a pretest and immediate posttest was not the best way to assess knowledge gain. What can be concluded for certain from this study is that there is a great need for more communication research to address methodological issues associated with life-span developmental changes in language due age (e.g., structural and processual speech comprehension) (Williams & Nussbaum, 2001).

The second contribution regards understanding predictors of behavioral intentions. According to the McGuire's theory, people process messages methodically through various stages starting with attention, moving to comprehension, followed by yielding, and eventually enacting the behavior. The numerous interactions among McGuire's message variables detected in this study suggest that the simple directional relationships of these variables with an outcome may be more complex than originally thought. Future research should be sensitive to understanding how different levels of each of the variables interact to explain message outcomes.

Limitations and Future Research

There are inherent challenges associated with conducting experimental studies with unique populations, such as rural, low-income, older adult women. One of the primary challenges is designing a study and creating a measurement instrument that underserved populations will understand and perceive as valid. One threat to the internal validity of this study was the number of participant reports that they tried "to remember what they said before" when answering the post-intervention questions, despite repeated explanations that the questionnaire was not a test. This brings up two important concerns with regard to research design and underserved populations. First, older adults are

frequently subjected to tests of their mental acuity during medical examinations. Thus, some of the participants in this study may have perceived the questionnaire as testing their ability to remember and recall information, despite numerous explanations to the contrary. Second, it is possible that some of the women had a high preference for self-consistency. As Cialdini and colleagues (1995) have noted, people who have a high preference for consistency are motivated to adhere to prior information. Thus, the pre test may have forced participants to form opinions on the topic of cancer clinical trials, which compelled them to attempt to answer in a similar manner on the posttest. Future research may want to investigate whether older adults and/or rural residents are more likely to exhibit a preference for consistency on questionnaires as compared to the general population. If this would be the case, it might help explain the small differences between the pre test and posttest scores.

Two related challenges was the dislike some participants had for the questionnaire component of the research. On several occasions, participants remarked that they couldn't say how they really felt using the closed-ended responses. It is unclear whether the discomfort was caused by the use of closed-ended questionnaires or having the questionnaires administered by an assistant. A similar concern is the comments made by a few participants that some of the questions were trying to be "tricky." Thus, participants would sometime appear to be carefully forming responses to avoid "falling" for whatever they perceived to be the trick. It is unclear whether this suspicion was related to the age, ruralness, or low SES of the population. Alternatively, it could be the combined influence of group memberships that are traditionally marginalized in the social sciences. For

example, for all but a handful of participants, this was the first “research study” they had ever participated in. For those who had previously participated in research, the studies were primarily situated in the biological sciences and precluded reporting individual thoughts and opinions. For some of the participants, participating in the project was a source of pride and novelty. Several participants made comments that they would be rushing home to tell friends and family that they had participated in research. Though although extremely positive attitudes toward participation predominated, research still constituted an “unknown” in a way that it does not to many undergraduates who participate in any number of studies in a given semester.

There is also the possibility that a desirability bias or a positivity bias influenced some of the data. The four female graduate students who served as lab assistants established a degree of rapport with each of the participants before they began the study. This may have led participants to avoid negative evaluations of the message out of politeness toward the research assistants. Alternatively, the power dynamics of the laboratory setting may have altered perceptions of the messages to be more positive than they might normally be in a medical setting. For example, feeling comfortable with the laboratory assistants and the setting or feeling special because of being given the opportunity to participate in a research study may have mitigated any differences that might normally exist in a physician’s office.

Another limitation related to measurement was the manipulation check items. The manipulation check was generally successful in that participants were able to correctly report whether or not the message they viewed included a particular metaphor (i.e., sex of

a baby or flip of coin). The problem was that, in addition to correctly identifying their particular metaphor, participants in the conventional and cultural metaphor conditions also reported that they remembered a doctor saying that randomization is a method used to ensure the research study is fair. However, this was the correct response only for participants in the definition condition. All the stimulus materials, it appears, led the participants to perceive randomization to be a procedure related to fairness. It may be that fairness was considered a socially desirable response, or that there was something about the research environment that led them to perceive that a research study would be fair. The result is that the fairness question measured perceptions of the fairness of randomization rather than the way randomization was actually explained, and thus was unable to distinguish between the definition and either of the two metaphor conditions.

A similar challenge was experienced with regard to physiological measurement. In spite of the numerous articles and resources that were consulted prior to endeavoring to collect physiological data with older adult women, none of these texts made mention of age-related problems with physiological data. These problems, as they were experienced in this study, related to the adhesion of electrodes to aged skin or body parts sized larger than usual. For example, loose skin or skin with many wrinkles made it very difficult to place the electrode flat on the skin. Engorged body parts, like might be expected with the water retention common to many physical ailments, provided a surface that protruded too much. This also prevented the proper adhesion of electrodes on the face, wrists, and ankles.

In conclusion, understanding how medically underserved populations process clinical trials messages is important both for social justice and improving the ability of clinical trials to recruit participants that are representative of the population with cancer. Some scholars have suggested that the key to increasing clinical trials participation among the medically underserved is increasing the number of physicians who recommend that patients participate in a clinical trial. This recommendation is based on the finding that many patients are likely to enroll in a clinical trial if the health care provider recommends this course of action (e.g., Kemeny, et al, 2003).

However, simply increasing the number of physicians who recommend participation in clinical trials is problematic for two reasons. First, many scholars have called into question the quality of informed consent that patients are giving (Brown, Butow, Ellis, Boyle, & Tattersall, in press). Second, we lack the ability to adequately explain clinical trials to patients in order to improve the informed consent process (Brown, Butow, Ellis, et al, in press). For example, research indicates that most patients do not have a firm understanding of the concept of randomization, which is also one of the primary reasons that patients report not participating in a clinical trial (e.g., Curbow, Fogarty, McDonnell, Chill, & Scott, in press). Thus, concrete recommendations need to be made to physicians about how to effectively explain clinical trials to patients in order to meet the dual goals of 1) increasing clinical trial participation and 2) maintaining the highest ethical standards when obtaining informed consent.

Based on the review of the literature on randomization, one might conclude that metaphors should be eliminated from medical discussion in order to avoid potential

confusion. Although metaphor is dependent on shared cultural knowledge and the competent creation and comprehension of metaphors becomes increasingly more difficult in intercultural interactions, we cannot forget that metaphor is also a powerful learning tool. Metaphors have the ability to help individuals understand concepts that a straightforward definition may not accomplish. Thus, it is unlikely that abandoning metaphors altogether will forward the goal of empowering patients to make informed decisions. Instead, future studies should continue to investigate the intersections of communication and health disparities. Specifically, further research is needed to understand the ways that language alienates underserved audiences from opportunities with the potential to benefit them (Marshall, Smith, & McKeon, 1995). In this way, the field of communication can play a key role in uncovering and reducing prejudice against people living in rural areas.

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Appendix A
Formative Interview Informed Consent

Title of Project: Semantic Barriers to Clinical Trials Accrual: Formative Interviews

Principal Investigator: Janice Raup-Krieger, M.A.
210 Sparks Building
University Park, PA 16802
E-mail: jlr339@psu.edu
Phone: 814-865-0945

Advisors:	Roxanne Parrott, Ph.D. 206 Sparks Building University Park, PA 16802 E-mail: rlp18@psu.edu Phone: 814-865-6255	Jon Nussbaum, Ph.D. 319 Sparks Building University Park, PA 16802 Email: jfn5@psu.edu Phone: 814-863-3619
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1. Purpose of the Study: The purpose of this research is to collect people's opinions about cancer clinical trials.
2. Procedures to be followed: Participation in this research will complete a face-to-face interview. As part of the interview, you will be asked to discuss your ideas and opinions about clinical trials. In order to make sure this research accurately reflects the opinions of the individual, the interview will be audio taped. These tapes will be kept until the research project is completed, at which time they will be destroyed (a time period that will not exceed 5 years).
3. Discomforts and Risks: The risks associated with this research are very minimal. However, you may experience slight discomfort because some of the questions ask you to think about topics that you may not be used to discussing. If you experience psychological distress of any sort upon completion of this study, you will be provided with the contact information for a counselor in your area.
4. Benefits: The benefits to participants include the opportunity to share your ideas about what information doctors should give their patients about cancer clinical trials, and access to free materials if you should want more information about cancer clinical trials. The benefits to society include the potential to improve a cancer patient's ability to make informed choices about his or her treatment.
5. Duration/Time: The interview will last approximately 1- 1.5 hours.
6. Statement of Confidentiality: Your participation in this research is confidential. Only the investigators in charge will have access to your identity and the audio associated

with this research project. In the event of publication of this research, no personally identifying information will be disclosed.

7. Right to Ask Questions: Participants have the right to ask questions and have those questions answered. If you have questions about your rights as a research participant, contact Penn State's Office for Research Protections at (814) 865-1775.
8. You will receive \$40.00 as compensation for the time and travel costs associated with participating in this study. If you choose not to participate in this study, you will receive \$20.00 as compensation for travel costs. If you are an employee of Penn State University, the compensation you receive for participation will be treated as taxable income and therefore taxes will be taken from the total amount. If you are not employed by Penn State University, total payments within one calendar year that exceed \$600 will require the University to annually report these payments to the IRS. This may require you to claim the compensation that you receive for participation in this study as taxable income.
9. Voluntary Participation: Participation is voluntary. Participants can withdraw from the study at any time by notifying the principal investigator. Participants can decline to answer specific questions.
10. Access to Research Report: If you wish to receive a copy of a report that explains the findings of the research project, please email jl339@psu.edu.

You must be 18 years of age or older to consent to participate in this research study. If you consent to participate in this research study and to the terms above, please sign your name and indicate the date below.

You will be given a copy of this consent form to keep for your records.

Participant Signature

Date

I, the undersigned, verify that the above informed consent procedure has been followed.

Investigator Signature

Date

Appendix B

Formative Interview Guide

1. Introduction to the study

The purpose of this study is to learn about women's cancer treatment experiences in this area. I would like to hear about your own experiences with cancer, as well as your opinions on ways we can improve communication with women about cancer treatment options.

2. As you know, I asked to interview you because you were diagnosed with cancer. Before we get to that, where are you originally from?

3. How long have you been living in this area?

4. Why did you choose to stay/move here?

5. What do you like the most about living here?

6. What do you like the least?

7. Fill in the following sentence with as many words as you can think of: "I am: _____."

8. One interest in of this research is to explore issues of identity. What do you consider to be most important in terms of your identity?

9. What groups do you identify with? What groups of people do you think are similar to you in some way?

10. In your opinion, how similar are you to other people in this area? You live in the Appalachian mountains. Do you consider yourself to be Appalachian?

11. How similar are you to other cancer survivors?

12. How similar are you to other people with the same occupation?

TRANSITION INTO DISCUSSION OF CANCER

13. How old were you when you were diagnosed with cancer?

14. Could you tell me a little more about how you were diagnosed?

- How long has it been since you were diagnosed?
 - How did your doctor tell you that you had cancer?
 - What terms or phrases did s/he use?

15. Did your physician say why you had cancer?
 - Do you think that other factors contributed to your cancer?
16. After you were diagnosed, what was your initial reaction?
 - What were you thinking?
 - How were you feeling?
17. What did you do during the first few days after your diagnosis?
 - Who did you tell?
 - Did you try to get more information on the disease?
18. Do you think that your diagnosis changed you in any way in the short term?
 - How you felt about yourself?
 - How you related to your family?
 - How you felt about the future?
19. When you were initially diagnosed, what did your physician say about potential treatments?
20. Did s/he present you with various options for treatment?
 - If yes, did s/he recommend a particular treatment?
 - If yes, how did s/he recommend you make your decision?
21. When your doctor discussed treatment, what types of questions did you have?
 - Did you have any concerns?
22. Did your doctor have any recommendations on how you could learn more about your treatment/treatment options?
 - Did s/he give you literature to read?
 - Did s/he recommend discussing your treatment with someone else who had the same treatment?
 - Did s/he recommend looking up the treatment on the internet?
23. Do you feel that you had enough information about the treatment the doctor chose/ to make a treatment decision?
24. If you were faced with a similar circumstance in the future, are there any other questions you would ask your doctor?
 - Where would you go for information?
25. How would you rate cancer care in this area?
 - What are the strengths of local cancer care?
 - What are the weaknesses?

26. In what ways do you think living in a rural area impacted your cancer experience?

27. Do you think your cancer care would have been better or worse if you had lived in a city like Philadelphia or Pittsburgh?

- Why?

Now we're going to shift gears a little bit. I'd like to talk to you about cancer research.

28. In your opinion, how effective are current approaches for treating cancer?

- Why?

29. In order for doctors to learn which medicines treat cancer most effectively, cancer patients volunteer to be in research studies. How important is it to you that doctors ask patients to participate in research studies to find more effective medicines for treating cancer?

- Who should be in these research studies?
- What makes it important/ not important?
- What other things might be more important to you?
- If your doctor had asked you to be in a research study, what would have been your initial reaction?
- What kind of questions would you have?

30. Research studies that help doctors determine which medicines work best for different types of cancer are called clinical trials. What do you think of when I say 'clinical trial'?

- What does the word 'clinical' mean to you?
- What does the word 'trial' mean to you?
- Have you heard of a clinical trial before?

I am going to read the definition of a clinical trial from this book and then ask you what you think about it.

Clinical trials are research studies involving people. They seek to answer specific scientific questions to find better ways to prevent, detect, and treat disease, and to improve care for people with diseases. Phase 3 clinical trials focus on learning how a new treatment compares to the standard or most widely accepted treatment. Researchers want to learn whether the new treatment is better than, the same as, or worse than the standard treatment. In order to do this, doctors give one group of patients in a medical study the standard treatment and give another group of people the new treatment and compare their results.

31. Based on this definition, what does the term clinical trial mean to you?
- If your doctor had read you this definition of a clinical trial and then asked if you would be interested in participating in a clinical trial, what would have said?
 - Does this definition make sense?
32. Have you heard any celebrities talk about clinical trials in the media?
- Have you heard of Lance Armstrong?

Over time, medical science learned that some people would prefer less risk and would choose the standard treatment over a new treatment even when it promises to be better. Some characteristics associated with people who avoid risk versus people who are willing to expose themselves to risk such as tendencies to be more conservative also could influence the health outcomes. Because it is important to have some people who are risk avoider and risk seekers in all treatment conditions and since differences in risk preferences are not the focus of study, then the decision of who is assigned to each group is randomly decided.

33. What is your opinion of how people are assigned to treatment?
34. If you had a friend who was considering participating in a clinical trial, how might you explain this process to her in your own words?
35. In this definition, it explains that people are assigned randomly to either receive the standard treatment or the new treatment. Another way to say that people are assigned randomly is to say they are assigned by chance, meaning they have an equal chance of being in either group. Do you think it is better to say that people are assigned randomly or to say they are assigned by chance?
- Why?
36. There are other ways to describe the process of being randomly assigned. I am going to give you a couple different ways for describing how a person might get picked to be in the treatment group. Please tell me what you like and dislike about each one:
- The doctor will flip a coin to decide whether you will be assigned to the treatment group or the control group.
 - The doctor will pick a number out of a hat to decide whether you will be assigned to the treatment group or the control group.
 - The doctor will roll a die to decide whether you will be assigned to the treatment group or the control group.

- Being assigned to the treatment group or the control group is like the lottery.
- A computer will decide whether you will be assigned to the treatment group or the control group instead of a doctor.

37. Now I am going to read all the choices again, and I would like you to tell me which one you like the most.

- What do you like about it?

38. Which one do you like the least?

- What don't you like about it?

39. Can you think of other ways to explain the process of being assigned to either the control group or the experimental group?

40. Do you think many people in this area know about cancer clinical trials?

- What do you think is the best way for people in this area to learn about clinical trials?

41. We are almost finished. Because this is a federal grant, I need to ask you a few additional questions.

- How old are you? _____
- How would you describe your racial/ethnic/ or cultural background?

- What is your occupation? _____
- How many people live in this house? _____
- I have to ask you two questions about your income.
 - Using your best guess, would you say that your annual income is more or less than \$xx.xx? _____
 - Using the following categories (show handout), which category would you fall into?

45. Those are all the questions that I have for you today. Is there anything else you would like to add before we finish?

Appendix C
Formative Focus Group Informed Consent

Title of Project: Semantic Barriers to Clinical Trials Accrual: Formative Focus Groups

Principal Investigator: Janice Raup-Krieger, M.A.
210 Sparks Building
University Park, PA 16802
E-mail: jlr339@psu.edu
Phone: 814-865-0945

Advisors:	Roxanne Parrott, Ph.D. 206 Sparks Building University Park, PA 16802 E-mail: rlp18@psu.edu Phone: 814-865-6255	Jon Nussbaum, Ph.D. 319 Sparks Building University Park, PA 16802 Email: jfn5@psu.edu Phone: 814-863-3619
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1. Purpose of the Study: The purpose of this research is to collect people's opinions about cancer clinical trials.
2. Procedures to be followed: Participation in this research will include being a part of a focus group discussion. As part of the focus group, you will be asked to discuss your ideas and opinions about clinical trials. In order to make sure this research reflects the opinions of the group accurately, the focus group discussion will be video and audio taped. These tapes will be kept until the research project is completed, at which time they will be destroyed (a time period that will not exceed 5 years).
3. Discomforts and Risks: The risks associated with this research are very minimal. However, you may experience slight discomfort because some of the questions ask you to think about topics that you may not be used to discussing. If you experience psychological distress of any sort upon completion of this study, you will be provided with the contact information for a counselor in your area.
4. Benefits: The benefits to participants include the opportunity to share your ideas about what information doctors should give their patients about cancer clinical trials, and access to free materials if you should want more information about cancer clinical trials. The benefits to society include the potential to improve a cancer patient's ability to make informed choices about his or her treatment.
5. Duration/Time: The focus group discussion will last approximately 1.5-2 hours. You will be provided with light refreshments, and you are free to take a break at any time.

6. **Statement of Confidentiality:** Your participation in this research is confidential. Only the investigators in charge will have access to your identity and the audio and videotapes associated with this research project. In the event of publication of this research, no personally identifying information will be disclosed. In addition, if participants speak about the contents of the focus group outside the group, it is expected that they will not reveal to other people what individual participants said.
7. **Right to Ask Questions:** Participants have the right to ask questions and have those questions answered. If you have questions about your rights as a research participant, contact Penn State's Office for Research Protections at (814) 865-1775.
8. You will receive \$40.00 as compensation for the time and travel costs associated with participating in this study. If you choose not to participate in this study, you will receive \$20.00 as compensation for travel costs. If you are an employee of Penn State University, the compensation you receive for participation will be treated as taxable income and therefore taxes will be taken from the total amount. If you are not employed by Penn State University, total payments within one calendar year that exceed \$600 will require the University to annually report these payments to the IRS. This may require you to claim the compensation that you receive for participation in this study as taxable income.
9. **Voluntary Participation:** Participation is voluntary. Participants can withdraw from the study at any time by notifying the principal investigator. Participants can decline to answer specific questions.
10. **Access to Research Report:** If you wish to receive a copy of a report that explains the findings of the research project, please email jlr339@psu.edu.

You must be 18 years of age or older to consent to participate in this research study. If you consent to participate in this research study and to the terms above, please sign your name and indicate the date below.

You will be given a copy of this consent form to keep for your records.

Participant Signature

Date

I, the undersigned, verify that the above informed consent procedure has been followed.

Investigator Signature

Date

Do you have Medicare? YES NO

Are you registered to vote? YES NO

Do you identify as a: DEMOCRAT REPUBLICAN INDEPENDENT

Have you ever had cancer? YES NO

IF YES, How old were you when you were diagnosed with cancer? _____

IF YES, What type of cancer did you have? _____

Do you have any relatives who have had cancer? YES NO

IF YES, please list how they are related to you [E.g., sister]

Do you have any good friends who have had cancer? YES NO

Are you involved in any activities related to cancer? YES NO
[E.g., Relay for life, cancer support group, etc.]

IF YES, please list what type of activities you do:

Which of the following categories best describes your annual household income?

A: \$10,000 or less D: \$30,001 to \$40,000 G: \$60,001 to \$70,000

B: \$10,001 to \$20,000 E: \$40,001 to \$50,000 H: Over \$70,000

C: \$20,001 to \$30,000 F: \$50,001 to \$60,000

PART 3: Please circle which word best represents your feelings about each of the following statements.

An important purpose of prayer is to get relief from my problems.

Strongly Disagree Disagree Neither Agree nor Disagree Agree Strongly Agree

Religion offers me comfort when misfortune strikes.

Strongly Disagree Disagree Neither Agree nor Disagree Agree Strongly Agree

A primary purpose of prayer is to gain protection.

Strongly Disagree Disagree Neither Agree nor Disagree Agree Strongly Agree

An important purpose of prayer is to gain acceptance of misfortune.

Strongly Disagree Disagree Neither Agree nor Disagree Agree Strongly Agree

I try hard to carry my religion over into all my other dealings in life.

Strongly Disagree Disagree Neither Agree nor Disagree Agree Strongly Agree

My religion is what lies behind my whole approach to life.

Strongly Disagree Disagree Neither Agree nor Disagree Agree Strongly Agree

Religion answers many questions about the meaning of life.

Strongly Disagree Disagree Neither Agree nor Disagree Agree Strongly Agree

Appendix E

Focus Group Moderator Guide

A. Introduction

Good evening, my name is Janice Krieger and I'll be your moderator this evening. Welcome to our focus group discussion tonight. A focus group is a small group discussion that focuses on a particular topic in depth. Tonight we will be talking about your thoughts and opinions regarding cancer. I'm not an expert in the topics we'll be discussing tonight, and I'm not here to give you information. I'm here to listen to your ideas and thoughts on these issues. In a focus group, there are no right or wrong answers, only opinions, and I'd like to hear from all of you about equally. It's important that I hear what each of you thinks, because your thoughts may be similar to those of many other people who aren't here at this table tonight. Your ideas are extremely important to us, and I'm interested in your comments and opinions. Please feel free to speak up even if you disagree with someone else here. It's OK to disagree, because it's helpful to hear different points of view. I'm also interested in any questions you may have as we go along. We have a lot of ground to cover in the next two hours, so, for the sake of time, I may jump ahead to the next topic from time to time, but please stop me if you want to add anything. We're audiotaping and videotaping our discussion. Everything you say is important to us, and we want to make sure we don't miss any comments. Later, we'll go through all of your comments and use them to prepare a report on our discussion. I want to assure you, however, that all of your comments are confidential and will be used only for research purposes. Nothing you say will be connected with your name. Also, if there are any questions you would prefer not to answer, please feel free not to respond to them. My colleague, Rachel, will be observing our focus group discussion.

B. Warm-Up

I'd like to begin by having each of you tell us your first name and a little bit about yourself.

C. Perceptions and Beliefs About Cancer

1. Now I'd like to talk specifically about cancer. If I had never heard of "cancer" before, how would you describe it to me? What is it?
2. [Draw stick figure on easel] This is Pat, and all we know about her is that she has cancer. I'd like to talk about how she came to have cancer. What do you think are some of the reasons why she might have gotten cancer?
3. Now that you've told me some possible causes of cancer, how do you think cancer actually develops in a person? How would you describe what happens inside the body? How do the things on our list actually cause cancer? (Probe: gene mutation/gene malfunctioning)
4. Do you have any idea how doctors know what causes cancer and what doesn't? How

do they go about finding out?

5. How do doctors find out what medicines will work in treating cancer and which one's won't?

D. Perceptions and Beliefs about Cancer Clinical Trials

Now, I'd like to read you a short story about a woman named Pat. Pat is not a real person, but the decision that Pat has to make could be similar to a decision that you or a family member or friend may have to make in the future.

Pat is a 65 year old woman who lives in Lewisburg who was just diagnosed with cancer. Pat's doctor has informed her that she needs to have a mastectomy. After her surgery, Pat will need follow-up treatment.

The doctor has given Pat two choices for her follow-up treatment. One option is for Pat to take tamoxifen for five years to help prevent the cancer from coming back. Pat also has the option of participating in a clinical trial, which is another name for a medical research study.

What comes to mind when you hear "clinical trial"?

Do you think it sounds better to call it a research study or a clinical trial?

Do you think that Pat should consider being in a research study?

What would be the benefits of being in a research study?

What would be the disadvantages?

Why do you think the doctor would offer Pat the option to be in a clinical trial?

What reasons do you think that doctors have for conducting medical research.

The doctor explains to Pat that only healthy women over the age of 50 without any major health problems other than cancer are accepted into this study. Because Pat meets all of these requirements, she has the choice of whether to be in the study or not. When Pat asks the doctor to explain more about the research study, she learns that some women in the study will take tamoxifen for five years and some will take tamoxifen for 10 years. The purpose of the study is to see if taking tamoxifen for ten years is better, worse, or the same as taking tamoxifen for five years in preventing the cancer from coming back.

The doctor also explained that this is a randomized clinical trial, which means that if Pat chooses to join the study, she can't choose which group she wants to be in. Instead, every woman who participates in the study will be assigned randomly to the group of women taking tamoxifen for five years or the group of women taking tamoxifen for ten years.

Instead of telling Pat that she would be put randomly to one of the groups, the doctor could have explained randomization in other ways. I am going to read you other ways of saying the same thing, and I'd like you to tell me if you like or don't like them.

Randomization is like flipping a coin will decide which treatment you receive.

Randomization means that one of two methods of treatment will be chosen by chance, and not by a decision made by the patient or the doctor.

Randomization is like drawing a number out of a hat to decide which treatment you receive.

The doctor in charge of the study will ask you to pick a marble out of a jar full of red and blue marbles. What color you pick will determine whether you are assigned to the 5 year treatment or the 10 year treatment.

Randomization means that the roll of a dice will decide which treatment you receive.

The doctor in charge of the study will put all the participants in a room and draw a line down the middle. The women on the right side of the room will be assigned to the 5 year treatment and the women on the left side of the room will be assigned to the 10 year treatment.

Being assigned to the 5 year treatment or the 10 year treatment is like the lottery.

Randomization means that you will be assigned to one of two treatments with equal chances of each treatments being the one you will receive.

*Randomization means that a computer will perform the equivalent of drawing names out of a hat. **OR** Randomization means that a computer will perform the equivalent of tossing a coin **OR** Randomization means that a computer will decide which treatment you receive. **OR** Randomization means that a computer will randomly allocate you to one of two possible methods of treatment.*

BE CAREFUL TO ASCERTAIN WHETHER PARTICIPANTS BELIEVE THAT THE COMPUTER IS TAKING PERSONAL INFORMATION INTO ACCOUNT WHEN MAKING THE DECISION.

All of these examples I gave you try to compare the process of being put into one of two groups when you have no choice to something that is easily understood, like flipping a coin. Often doctors compare participating in research studies to more familiar objects or activities to make it easier for people to understand. If you were the doctor, what would you compare it to help your patients understand?

If you were Pat, would you agree to be in this research study? Why or Why not?

Thank participants & hand-out information packets.

Appendix F

Transcript of *Cancer Trials: Because Lives Depend On It*

Debbie Gurley: I'll never forget March 10th, the day I was sitting in the oncologist's office... and he said the cancer has spread. And I just couldn't believe it was happening to me... I felt so stunned and so devastated... I couldn't even cry.

Wilbur Crable: My father died with it and my first cousin died with it... And I sort of figured it was in the family. So I figured it would be of my interest to get involved in a program like this. So that's why I did it.

NARRATOR: The Crables: The Gurleys. Two families whose lives were touched by cancer. And two families *empowered* by cancer clinical trials. Some, empowered to benefit from new treatment options. And all empowered to help others—young and old, sick and healthy, urban and rural, and everywhere in between. Empowerment, access, and options. That's what clinical trials—and the people who make them happen are all about.

Debbie Gurley: ...once you gather the information and you start to see that there are different roads you may choose to go down, umm, you feel empowered. You feel like it's not so out of control anymore.

Narrator: And one of those roads is participating in a research study called a clinical trial.

Dr. Hayden Braine: A clinical trial is a test to see if a drug or treatment will be effective in treating human disease.

One hundred percent of the people who take a medicine or a treatment for a disease are standing on the shoulders of someone who participated in a clinical trial.

Dr. Richard Klausner: The clinical trials process is the only way where we learn how to improve therapies—both to make them more effective and to make them less toxic.

Christine Crable: When Wilbur first mentioned the fact that he wanted to participate in this trial I thought it was a good idea ... but if you don't volunteer to help to advance medicine we'll be at a standstill. By volunteering you're helping not only yourself but you're helping many others.

NARRATOR: Helping—by being part of the link that turns the breakthroughs in research into new effective treatments for the *future*. And in the *present*, clinical trials often give people facing cancer access to treatment options they might not otherwise have.

Dr. Atkins: When I look at a patient who has cancer, there's a number of ways you can look at it... From my perspective, the clinical trials represent the state-of-the-art.

Evelyn Westbrook: We wanted the latest medication, the latest procedures, the latest information that we could get.

Janie Powell: He just wanted to get well, and that was the main thing. And if this was going to help him, this is what we would have done, you know.

Debbie Gurley: I happen to think that clinical trials are the cutting edge. That's where the great advances are coming from. I mean after all, that's where the research is being done.

NARRATOR: But cancer research trials aren't only for people seeking the cutting edge because their cancer has advanced—or because their alternatives are limited.

Dr. Huerta: Cancer has many stages. Cancer is a very complicated disease. Every stage in the development of cancer is able to have a clinical trial. There are clinical trials for prevention of cancer... people who, they don't have no cancer... There are clinical trials for initial treatments. There are clinical trials for patients who are relapsing... they are for the first time. There are clinical trials for patients who are relapsing the second time. So it is not true that there are clinical trials only for people in the final stages of the disease.

NARRATOR: Cancer clinical trials don't involve only participants with cancer. There are also clinical trials that invite healthy people who *don't have cancer* to look at ways they can prevent the disease. The idea that clinical trials are only for the very ill is one of

many misconceptions surrounding clinical trials. Another myth—based on fear—is the myth that patients are kept uninformed and treated like guinea pigs.

Debbie Gurley: When I tell other people that I've been involved in a clinical trial that's actually been said to me before. You know, oh, I could never do that because you know they're just trying out weird stuff on people and that's really not true. There are no surprises in a clinical trial as far as I'm concerned

NARRATOR: Reservations, questions, and risks. They all must be considered, and addressed thoroughly.

Dr. Klausner: In a clinical trial, there is a formal and required structure to attempt to define the risk, to communicate the risk, and to be sure that the patients (the participants) *understand* the risks.

Dr. Liu: The discussion of risk in clinical trials is highly dependent on the type of study we are dealing with. In early exploratory studies, the risk may be very high. In late studies, where we know all the risks that are involved and we are only comparing the benefits, then the risk is actually relatively low. So one has to view the discussion of risk or conduct a discussion of risk in the context of the type of studies that are being done.

NARRATOR: Like the myth about patients receiving little or no information about risks, another misconception involves the use of placebos—or sugar pills—in place of treatments that patients may need.

Dr. Braine: We never use a placebo in place of an active treatment that the patient needs. If a patient needs a treatment, they get that treatment. We would then add in the trial other treatments to it for comparison purposes.

NARRATOR: Regardless of which treatment patients receive, a group called an Institutional Review Board approves and monitors clinical studies to ensure that they're conducted ethically and responsibly.

Dr. Klausner: An IRB or an Institutional Review Board is set up legally and is required to approve any study that involves human beings. They approve it to make sure that the rights and the health and safety of patients are maximally protected—that there's a procedure in place to make sure that the participants, the patients are fully informed and that there is a process to oversee the clinical trial to make sure that the agreed-upon patient protections are actually carried out.

NARRATOR: In addition to protecting *patients' rights*, the review board ensures that the study helps the *right patients*. Not everyone can participate in a clinical trial.

Whether you're healthy or ill, you must fit the study's requirements. And you must make an *informed* choice. That means considering medical questions—and nonmedical questions...

Toni Wells: You may have to travel a long distance. Is that going to fit in with your lifestyle? You may be the breadwinner in your family. How's that going to impact? And so all of that is laid out before the patient so they can decide.

Norman Westbrook: I made my decisions upon ... actually upon the recommendations of the doctors, really, if you want to know the truth

Narrator: Doctors are *one* key source of information, but not the *only* source.

Toni Wells: Many patients will go on the Internet. They will check the newspapers. They will go to the library. They'll research the disease themselves and find out what the state of the art treatment is.

Debbie Gurley: I'm convinced that for cancer patients especially it's absolutely vital to not turn over what's gonna happen to you, to your health, and just put it in somebody's hands and say you know you deal with it, you make me well

Dr. Atkins: I think patients need to demand clinical trials, if there's one open for them. And they need to sort of demand that their doctor be active in the clinical trial process.

Dr. Hayden Braine: I hope more people would participate in trials so that we can move knowledge in the field along faster and so that we can deliver these new treatments that are coming along—and this is going to become more and more important in the upcoming decade.

Narrator: Important to everyone—every age and from every place. Because cancer touches all of us. And cancer clinical trials benefit all of us.

Wilbur Crable: How can they find out cures to many of these things without going through this process? So somebody has to do it. And I'm willing to do it.

Debbie Gurley: How many times can you do something that's helpful to you but unselfish in helping other people too?

NARRATOR: For more information call the National Cancer Institute's Cancer Information Service at 1-800-4 CANCEER or visit our Web site, www.cancer.gov

Appendix G
Transcript of Stimulus Video(s)¹¹

Hi. I'm Dr. Brett Oesterling. I'm a family doctor in rural Central Pennsylvania. You've just heard the stories of several cancer patients who chose to be in research studies. As a doctor, I know how important cancer research studies are. That's why I'd like to take the next few minutes and help you understand what a cancer research study is and how it works.

There are many different types of research studies. Today, I'm focusing on research studies that compare new treatments for cancer to the treatments we are currently using. These research studies offer people the latest treatment for their cancer. They also help doctors learn more about how to treat people with cancer. All of the treatments helping people today were once part of a research study.

Let me tell you about the process of developing new treatments for cancer. First, scientists work in the laboratory to discover a new treatment. Then, doctors have to conduct a series of studies with people to be certain the treatment will help patients. The first type of research study, called Phase I, makes sure that the new treatment is **safe** to use in patients. The second study, called Phase II, determines **how much** of the treatment to use. At this point, we know that the treatment is safe, but we're not sure if is really better than treatments that are already being used. In the third type of research study, called Phase III, doctors compare the new treatment to the current treatment to see which one is better.

¹¹ Bold text indicates the paragraph of the script that was manipulated to create the different message conditions. The exact wording of each manipulation appears at the end of the transcript.

In other words, some people in Phase III research studies get the new treatment, while the others get a treatment that a doctor would usually prescribe. Doctors call patients who receive the new treatment the "treatment group". Doctors call patients who receive the usual treatment the "control group" or "comparison" group" because they are comparing the new treatment against the one people normally get. These terms are confusing because it sounds like only one group gets treatment. But that's not the case. Everyone in a cancer treatment research study gets treatment. It's just that some people get the new treatment and some get the treatment that's already in use.

An important part of a Phase III research study is that a patient does not get to pick which group to be in. This is because doctors use a process called randomization to make sure that the groups are about the same. **Randomization is a method used to ensure the research study is fair. It means that patients are assigned by chance to different treatment groups. Each patient in a randomized study has an equal possibility of being put in one of two groups. Sometimes there are more than two groups. In a treatment study, a patient will either be in the group taking the new treatment called the treatment group or the group taking the usual treatment called the control or comparison group. Every patient in a randomized study will get treatment for his or her cancer.**

I hope that you and your loved ones will never need to make a decision about cancer treatment. But if you do, I hope that you will ask your cancer doctor to tell you about all your treatment options. Ask if there is a research study that might be right for you. Remember, if you are in a clinical treatment study, you will always get treatment for

your cancer. You will be given either the new treatment, or the treatment that is now being used. I hope you now understand the important role of cancer research studies in helping people with cancer and how this information can help you or someone you love.

Definition condition:

Randomization is a method used to ensure the research study is fair. It means that patients are assigned by chance to different treatment groups. Each patient in a randomized study has an equal possibility of being put in one of these two groups. Sometimes there are more than two groups. In a treatment research study, a patient will either be in the group taking the new treatment called the treatment group or the group taking the usual treatment called the control or comparison group. Every patient in a randomized study will get treatment for his or her cancer.

Conventional metaphor condition:

Randomization is like the flip of a coin. The possibility of getting heads is the same as the possibility of getting tails. Each patient in a randomized study has an equal possibility of being put in one of two groups. Sometimes there are more than two groups. In a treatment research study, a patient will either be in the group taking the new treatment called the treatment group or the group taking the usual treatment called the control or comparison group. Every patient in a randomized study will get treatment for his or her cancer.

Cultural metaphor condition:

Randomization is like the sex of a baby. The possibility of a boy is the same as the possibility of a girl. Each patient in a randomized study has an equal possibility of being put in one of two groups. Sometimes there are more than two groups. In a treatment research study, a patient will either be in the group taking the new treatment called the treatment group or the group taking the usual treatment called the control or comparison group. Every patient in a randomized study will get treatment for his or her cancer.

Appendix H

Laboratory Protocol

Participant Arrival

Thank-you so much for coming today Ms. [*last name*]. SHAKE HANDS. My name is [*lab assistant first and last name*]. It is very nice to meet you. Did you find the parking garage ok? Great. Do you have a cell phone? If so, please turn it off until you complete the study.

We are so glad you are interested in participating in this study. The goal of this study is to help women with cancer by learning the best way to inform them about treatments. By participating in this study, you will be helping doctors communicate better with their patients, which can help improve medical care for everyone.

I would like to give you an overview of what is going to happen during the next hour so you know what to expect. First, I am going to give you a form to read and sign that describes your rights as a research participant [*show informed consent document*]. After that, I will ask you to answer a few short questions [*show questionnaire*]. Next, we will go into the next room [*point to viewing room*] where you will watch a thirteen minute video that will give you information about cancer research studies. While you are watching the video, we would like you to wear patches that will tell us things like how fast your heart is beating and your facial expressions. The patches are often used here at Penn State to learn how people respond to movies and television shows.

I will be helping you put patches that look like this [*show electrode*] on your wrist, ankles, forehead, and cheek. Some people find the patches to be a little itchy, but I went through the study and I can assure you that they are safe and don't hurt. They have a little gel in the center will help the computer read your responses. First, I will rub a sponge over your skin like this which will help the patch stay on your skin [*demonstrate on wrist*]. Then, I will put the patches on [*demonstrate electrode placement on wrist*] and connect them to the computer. I will also put these [*demonstrate placement of GSR electrodes*] on two of your fingers. Like the patches, they will have a little gel on them. After you watch the video, I will help you remove the patches [*demonstrate removing the electrodes*]. I will ask you a few more questions and then we will be done [*show questionnaire*]. This study is funded by the government, so when you complete the study, I will pay you \$65.00 for participating. The whole study should take about 1 hour to complete.

There are a few factors that can prevent the patches from doing what they are supposed to. Because of this, I need to ask you a few questions:

Do you have any make-up or lotion on your face?

Are you wearing any jewelry today?

Do you have a pacemaker?

Do you have any metal in your body, such as rods or pins?
 [Check for external hearing aid]

Before we get started, I am going to give you two copies of this form that describes your rights as a research participant. Please read & sign both of these forms. You will give one copy back to me and keep the other copy for your records.

Thank-you. [Collect one copy of informed consent]

Next, I would like to ask you some questions. After each one, please tell me how you would answer the question. If you aren't sure about a question, just answer it the best you can.

Thank-you Ms. [name]. Before we go into the next room, I would like to ask you to go into the ladies room and wipe your cheeks and forehead with one of these facial cloths. This will help us get a more accurate reading. After that, please wash and dry your hands. This will help the electrodes we place on your fingers stay on better too.

Please follow me into the next room. Have a seat right here in front of the television. This is where you will be watching the video.

Before I turn on the video, I am going to put on the monitors. I am going to start by putting the monitors on your forehead, and then we will put them on your cheek. If anything feels uncomfortable to you, please let me know.

- BE AWARE OF ANY FACIAL PARALYSIS OR TICKS
- IF NEEDED, SECURE HAIR AWAY FROM THEIR FACE (bobbypin)
- ASK PARTICIPANT TO FROWN
- Place ground electrode on middle of forehead
- Place negative electrode on low part of eyebrow (like a unibrow)
- Place hot electrode on high part of eyebrow (tip: red hot high)
- ASK PARTICIPANT TO SMILE
- Place negative electrode on low part of cheek
- Place hot electrode on high part of cheek (may overlap)

Now I am going to put a monitor on your ankles and your right wrist. In order to do that, we will need to roll your pant leg a bit. Would you like me to assist you with that?

[As you look for the vein...] These monitors will tell me how fast your heart is beating. The best way to do that is to put the monitor on your skin near a vein. Some people's veins are easier to see than others, so that is what I am looking for.

- Find vein in right ankle, buff, and attach electrode
- Find vein in left ankle, buff, and attach electrode

- Find vein in right wrist, buff, and attach electrode
- TRY TWICE TO FIND VEIN AND THEN EDUCATED GUESS.
- Remember:
- Channel 1: EMG
- Channel 2: EMG
- Channel 3: GSR
- Channel 4: ECG
- Attach the **black (ground)** lead to the forehead
- Attach the **white** lead to the **negative** eyebrow electrode (low)
- Attach the **red** lead to the **hot** eyebrow electrode (high)
- Attach the **white** lead to the **negative** cheek electrode (low)
- Attach the **red** lead to the **hot** cheek electrode (high)
- Attach **black (ground)** lead to right ankle
- Attach **white** lead to right wrist electrode
- Attach **red** lead to left ankle

I am going to tuck these wires behind your ear and clip them to your collar because I find it to be more comfortable that way.

Now, I am going to put the monitors on your fingers. I need the second and third finger on your left hand. I am going to put just a dab of this gel in the monitor.

- Align transistors with dip in fingers on LEFT hand and attach securely

Great. Everything looks good. Now I am going to double-check that the monitors are doing their job. Excuse me for a minute please.

- Click **start** on the computer

Mrs. Smith, could you please give me a big smile? Good. How about a frown?
Perfect.

- Check readings on GSR & ECG. If something isn't right, say "Ms. [name], I put this on a little too much to the right. I am going to try to adjust it." If you can't see GSR display, click display then autoscale. This stops the recording.
- Dim lights in viewing room (slightly below halfway)
- Turn off lights in control room

Mrs. Smith, I am going to start the video now. The video is only about 10 minutes long. Once the video is over, I will come in and help you remove the monitors.

I want to make sure that you can hear the video without it being too loud. Once the video starts, please give me a thumbs up if you need me to turn up the volume. If you need me to turn down the volume, give me a thumbs down.

- Keep door open
- Press play on DVD & on the computer **at the same time.**
- *AT THE END OF THE VIDEO:*
- Press Stop on the computer
- Turn on lights
- Remove finger transistors & hand participants a paper towel
- Remove leads (**MAKE SURE GROUND/BLACK WIRE IS LAST**)
- Remove electrodes (COUNT TO MAKE SURE YOU HAVE 8)
- Escort participant to waiting room

Now that you have watched the video, I would like to ask you a few more questions.

- READ THROUGH posttest with participant

Great. We are all finished. As Janice told you on the phone, you will be paid \$65.00 for participating in this study. I am going to go get the money now. If you would like to wash your face, you are welcome to go the ladies room.

- Return to computer room and privately retrieve envelope from lock box

Thank-you so much for taking part in this study. Wait right here and I will go get your money for participating [*Count out money to participant and place back in the envelope*].

Because this study is funded by the government, I need you to sign this paper that verifies that you have received \$65.00 for participating. This copy is for you to keep for your records.

Thanks again Ms. [*name*]. Would you be interested in receiving the results of our research when it is finished? If so, please write your name and address here. If you know any friends that might be interested in participating in this study, please feel free to take a flyer and ask them to contact Janice to sign up. When you take the elevator, you will want to press “G” to get to the ground floor. Have a good day.

Appendix I
Laboratory study informed consent

Title of Project: Cancer C.A.R.E. in our Community

Principal Investigator: Janice Raup-Krieger, M.A.
210 Sparks Building
University Park, PA 16802
E-mail: jlr339@psu.edu
Phone: 814-865-0945

Advisors:	Roxanne Parrott, Ph.D. 206 Sparks Building University Park, PA 16802 E-mail: rlp18@psu.edu Phone: 814-865-6255	Jon Nussbaum, Ph.D. 319 Sparks Building University Park, PA 16802 Email: jfn5@psu.edu Phone: 814-863-3619
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1. **What is the purpose of the study?** The purpose of the study is to find better ways to explain cancer treatment options. The study will measure how people react to a video about cancer research studies. Reactions include changes in heart rate or facial expression. There will be about 150 women in this study.
2. **What does the study involve?** People in the study will answer two sets of written questions and watch a short video. The video is about cancer research studies. People in the study will have monitors on their finger, wrists, ankles, and face.
3. **What are the discomforts and risks?** There is no risk of pain or physical discomfort. The monitors used in this study are safe.
4. **What are the benefits?** People in the study will learn about cancer treatment options. This information may help them or someone they love in the future. People in the study are also helping doctors learn how to communicate better with their cancer patients.
5. **How long will this study take to complete?** About 1 hour.
6. **Is my name kept private?** Yes. Only the person in charge and assistants will have access to the name and other personal information of people in the study. Personal information will not be shared if this research is published or presented. The Office for Research Protections and the Biomedical Institutional Review Board may review records related to this project.
7. **Do I have the right to ask questions?** Yes. Contact Janice Krieger at 865-0945 if you have questions about this study. Contact Penn State University's Office for Research Protections at (814) 865-1775 if you questions about your rights as a person in the study.

9. **Will I be paid for my time and the cost of travel?** Yes. You will be paid \$50.00 when you finish the study. You will receive an extra \$15.00 to cover the cost of gas and parking.

10. **Is being in the study voluntary?** Yes. You can stop at any time. You do not have to answer any questions you do not want to answer.

11. **What if I am hurt?** It is unlikely that you will be hurt during this study. If you are, medical care is available. However, the University will not provide free medical care or financial payment. Signing this document does not waive your rights against The Pennsylvania State University if you are injured as a result of negligence of the University or its researchers.

You must be 18 years of age or older to be in this study. Please sign your name and date below if you agree to be in the research study described above.

You will be given a copy of this signed and dated consent for your records.

Participant Signature

Date

Person Obtaining Consent

Date

Appendix J

Rural Identity Measure

1. I feel at home in rural Pennsylvania.
2. I feel like I belong in rural Pennsylvania.
3. I am proud to live in rural Pennsylvania.
4. Living in rural Pennsylvania is an important part of who I am.
5. I would like to live in rural Pennsylvania forever.
6. I identify with other people who live in rural Pennsylvania.

Appendix K

Religiosity Measures

Intrinsic religiosity

1. I try hard to carry my religion over into all my other dealings in life.
2. My religion is what lies behind my whole approach to life.
3. Religion answers many questions about the meaning of life.

Extrinsic religiosity

1. An important purpose of prayer is to get relief from my problems.
2. Religion offers me comfort when misfortune strikes.
3. A primary purpose of prayer is to gain protection.
4. An important purpose of prayer is to gain acceptance of misfortune.

Appendix L

General Attention Measure

1. Do you remember the video you watched discussing treatment for cancer?
2. Do you remember a doctor in the video saying that he was from Pennsylvania?
3. Do you remember a doctor in the video explaining medical research studies?
4. Do you remember a doctor in the video explaining randomization?

Appendix M

Randomization Knowledge Measure

1. In a clinical trial, randomization means that patients have an equal chance of being assigned to each treatment being tested.
2. Randomization means that patients in a clinical trial are allowed to choose treatment out of a list of options. **R**
3. The goal of a clinical trial is to match people to the best treatment for them. **R**
4. Randomized trials are the best way to find out whether one treatment is better than another.
5. In a randomized trial, the treatment you get is decided by chance.

Note: **R**= reverse-coded item.

Appendix N

Message Induced Arousal Measure

Question stem: The doctor's explanation of randomization made me feel...

1. Sad
2. worried
3. tense
4. anxious

Appendix O

Behavioral Intention Measure

1. If I was diagnosed with cancer, I would want to participate in a clinical trial for a new treatment.
2. If I was diagnosed with cancer, I would want to participate in a clinical trial for my initial treatment.
3. If I was diagnosed with cancer, I would want to participate in a clinical trial if my initial treatment failed.
4. If I did not have cancer and was asked to participate in a clinical trial to prevent cancer, I would be willing to participate.
5. If a family member was diagnosed with cancer, I would want him/her to participate in a clinical trial for a new treatment.
6. If a close friend was diagnosed with cancer, I would want him/her to participate in a clinical trial for a new treatment.
7. If a family member was diagnosed with cancer, I would suggest they find information on cancer research studies.
8. If a close friend was diagnosed with cancer, I would suggest they find information on cancer research studies.

Vitae
Janice Raup Krieger

Education

PhD: *Communication Arts & Sciences*, The Pennsylvania State University, 2007

MA: *Speech Communication*, The Pennsylvania State University, 2001

BA: *Communication*, cum laude, Indiana Wesleyan University, 1999

BA: *Spanish*, cum laude, Indiana Wesleyan University, 1999

Employment

Assistant Professor, School of Communication, The Ohio State University

Publications

Krieger, J.L., Parrott, R.L., & Afifi, W. (2006). Missed opportunities in college alcohol education programs: The Role of perceived control. *Communication Research Reports*, 23(4). 239-249.

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Grants

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