

**COMMUNITY-BASED OUTREACH AND RECRUITMENT OF AFRICAN AMERICAN
ELDERS FOR HEALTH RESEARCH AND HEALTH IMPROVEMENT
PROGRAMMING: A SYSTEMS THEORY PERSPECTIVE**

by

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This thesis provides a systems theory perspective regarding outreach and recruitment efforts targeting African American elders for health research and programming. A literature review describes the barriers and facilitators of participation on multiple system levels that have been described in existing research. Five models of recruitment are presented. The literature review also provides a listing of existing systems theories and a description of one systems theory in particular—complex adaptive systems—while adding some additional elements from system dynamics.

An IRB approved exempt status review of existing community meeting minutes is also described. The meetings took place during my master's practicum at Hosanna House, Inc., a community center in Wilkinsburg Borough, Pennsylvania. The meetings revolved around programming for seniors in Wilkinsburg, a neighborhood that is predominantly African American. Research participation and communication and outreach approaches were also discussed with community members at these meetings. The discussions confirm, in a real world setting, some of the barriers and facilitators found in the literature.

The literature review and the review of the meeting minutes provide the basis for recommendations for a systems theory approach to community-based outreach recruitment in a setting such as Wilkinsburg. Taking such an approach may allow public health practitioners and researchers to be more effective at encouraging participation in health research and health improvement programming. This is of great public health significance as African Americans and

the elderly continue to experience significant health disparities. Encouraging participation can improve the health status of this underserved population and hopefully serve to eliminate health disparities. This is an ethical necessity in the field of public health.

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PREFACE

I would like to gratefully acknowledge the following people for their assistance with this thesis: Barbara Folb, MM, MLS, Public Health Librarian, in the Health Science Library System at the University of Pittsburgh for her consultative services regarding my literature review; Emily Galbreth, Development Associate and Steve Hellner-Burris, Director of Development, for their guidance during my practicum at Hosanna House and for their permission to review the data from community meetings held during my practicum; the community members who graciously gave of their time to participate in the community meetings held during my practicum; the members of my committee for their feedback regarding my thesis and frequent guidance throughout my master's studies; to Thomas and Fran, the best Thesis Support Group (TSG) I could ask for; to my best friends April and Jocelyn for helping to keep me social; and to my family for their love and support and already thinking I should get a PhD.

I would also like to provide a note here regarding some nomenclature. There is no clear pattern in the literature reviewed regarding the use of terminology referring to “blacks” and / or “African Americans”, and frequently, the articles reviewed provide no definition of their use of the terms. I have tended to use them interchangeably throughout this thesis, and when referring to a particular book, chapter, or journal article, I have used the term of that particular author or group of authors. I have tried to focus the majority of the literature reviewed on African

Americans. However, much of the literature lumps many minority groups together. Thus, in some sections of this thesis, I refer to “minorities”. This means I could not make any specific statements regarding African Americans based on the literature.

In addition, I have used the terms elders, elderly, and seniors interchangeably. In the majority of the literature found, these terms refer to people aged 65 or older, and that is how I will use those terms as well. If a particular age group is mentioned that does not fall within those boundaries, I have noted it in the text.

Finally, the vocabulary of systems theories is likely a new one for many public health practitioners; therefore I will provide those definitions in the background section of this thesis.

1.0 INTRODUCTION

Disparities in health among various segments of society are enough of a problem within the United States to be directly addressed by *Healthy People 2010*, the country's health agenda for the period 2000-2010. *Healthy People 2010* states two overarching health goals for the U.S.: increasing quality and years of healthy life and eliminating health disparities (U.S. Department of Health and Human Services (DHHS), 2000). These main goals are operationalized through 28 focus areas and 467 specific objectives. *Healthy People 2010* presents health as being contextual within the community and promotes a vision of "healthy people in healthy communities" (U.S. DHHS, 2000, p. 3). In line with this community health approach, DHHS produced a guide for communities to assist them in implementing *Healthy People 2010* objectives (2001). DHHS also conducted its *Midcourse Review of Healthy People 2010*, which precipitated some changes in data sources for and wording of objectives (2006). Despite the community guide and ongoing evaluation of *Healthy People 2010* efforts, the Agency for Healthcare Research and Quality's (AHRQ) *2006 National Healthcare Disparities Report* indicates that health disparities are an ongoing problem.

From an ethical perspective, the field of public health has a lot to say about health disparities. Following a brief overview of health disparities, I will discuss the public health ethical issues related to disparities. Finally, I will examine why it is so difficult to

outreach to and recruit into clinical services and health research African American elderly and whether taking a systems perspective can suggest ways to ameliorate the situation. The elimination of health disparities is ultimately why we should care about outreach and recruitment of special populations.

1.1 HEALTH DISPARITIES

The AHRQ 2006 report discusses disparities in relation to four aspects of quality including effectiveness, patient safety, timeliness, and patient centeredness. These aspects of quality are defined by various measures as is access to care. Blacks fare poorer than whites on two of six access measures, and those who are poor do worse than high income individuals on all six access measures. The good news in this area is minimal as the situation for blacks is improving on three of five access indicators and one of four quality indicators. But unfortunately, the situation for blacks is declining on one of three quality indicators; and the poor are worse off on three of five access indicators and eight of twelve quality indicators. AHRQ states that these findings hold across primary, secondary, and tertiary prevention and a variety of disease states.

Much research has shown health disparities based on race, income, and potentially other variables such as age and gender (AHRQ, 2003; AHRQ 2006; Schulman, Berlin, Harless, Kerner, Sistrunk, Gersh, et al., 1999; Chen, Rathore, Radford, Wang, & Krumholz, 2001; Smedley, Stith, & Nelson, 2003). Race and socioeconomic status (SES) (and its component variables such as income, education, job attainment, and the like) are closely linked to health outcomes. For example, a greater proportion of non-

Hispanic whites have bachelor's degrees than blacks, unemployment is higher among blacks than whites, and the rate of blacks living below the poverty rate is about three times the rate for whites (McKinnon, 2003). Farmer and Ferraro (2004) report there is evidence that race and SES independently affect health outcomes, but there is also evidence that the effect of SES on health is different by race. The authors found that equal improvement in SES for blacks and whites does not result in equal improvements in self-reported health status. In fact, the difference in self-reported health status between blacks and whites was greatest between the highest educated blacks and whites, with blacks reporting significantly poorer health status (Farmer & Ferraro, 2004).

Given that the scope of this thesis focuses primarily on African American elders (many of whom are low-income), I will concentrate here on disparities related to those variables. This is not meant to be an exhaustive summary of health disparities. I will merely review highlights of the AHRQ reports supplemented by some additional findings from the literature. For a more extensive discussion of this topic, one can refer to *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, a Congressionally commissioned report by the Institute of Medicine (IOM) (Smedley, et al., 2003).

Disparities exist in preventive care. Black elders are less likely than white elders to receive the flu vaccine, as are poor individuals (AHRQ, 2006; Chen, Diamant, Pourat, & Kagawa-Singer, 2005). Black elders are also less likely than white elders to have ever gotten the pneumonia vaccine (AHRQ, 2006). Black women and poor women are less likely than white women and high income women to get mammograms to screen for breast cancer (AHRQ, 2003); similarly, colorectal cancer screening rates among adults

aged 50 and older are significantly lower in blacks compared to whites and the poor compared to those with high income (AHRQ, 2006).

AHRQ also reports disparities in the management of disease. In terms of diabetes care, the proportion of blacks with controlled hemoglobin A1c (a long term measure of blood sugar) is significantly lower than the proportion for whites (AHRQ, 2006). Blacks and poor individuals with diabetes are less likely than whites and high income individuals to have their blood pressure under control or to receive adequate hemodialysis for end-stage renal disease (AHRQ, 2006). In 2004, the rate of new AIDS cases among blacks was three times higher than the rate in whites during 2004 (AHRQ, 2006). Disparities also exist with nursing home, home health, and hospice care (AHRQ, 2006).

Some research has found that African Americans may be treated differently by doctors. For example, a lower proportion of overweight blacks than whites are counseled by their doctors regarding this issue (AHRQ, 2006). Schulman and colleagues (1999) reported that doctors are less likely to refer blacks than whites for cardiac catheterization given chest pain; the investigators also found an interaction of gender with race whereby black women were significantly less likely than white men to be referred for cardiac catheterization. Chen and colleagues (2001) found that blacks are referred for cardiac catheterization following an acute myocardial infarction at lower rates than whites, and this occurs independently of whether the physician is black or white.

1.2 PUBLIC HEALTH ETHICS AND HEALTH DISPARITIES

Underpinning the concern regarding health disparities are two main principles: the notion of health as a human right and the importance of health equity. The Public Health Leadership Society's (PHLS) publication *Principles for the ethical practice of public health* (2002), details the ethical obligations of public health practitioners. Of primary importance, the PHLS views health through a human rights lens. This echoes the view of the World Health Organization whose Constitution states, "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic, or social condition" (2006, p. 2). PHLS states that advocacy for the public is a key ethical principle, especially for people who cannot help themselves (2002). In addition, there is an obligation on the part of the practitioner to share with the community what is known and to act once knowledge is available (PHLS, 2002; Thomas, 2004). Thus, based on its ethical canon, and given that so much research has found the existence of health disparities, the field of public health must act to protect the health rights of those who are experiencing differentially poor outcomes. Braveman and Gruskin address the issue of health equity in their 2003 publication, "Defining equity in health." The article examines what is meant by health equity. They settle upon the following definition: "the absence of systematic disparities in health (or in the major social determinants of health) between social groups who have different levels of underlying social advantage / disadvantage—that is, different positions in a social hierarchy" (p. 254). The authors argue that if a health situation is equitable, there is equal opportunity for health among various groups (Braveman & Gruskin, 2003). It is not enough that health outcomes occur differentially

because some of this is expected. For instance, the incidence of Alzheimer's disease increases with age not because of inequitable health situations, but because age is the primary risk factor for developing the disease. For there to be a true disparity, the difference must be unjust and systematic. As Braveman and Gruskin (2003) state:

A health disparity between more and less advantaged population groups constitutes an inequity *not* because we know the proximate causes of that disparity and judge them to be unjust, but rather because the disparity is strongly associated with unjust social structures; those structures systematically put disadvantaged groups at generally increased risk of ill health and also generally compound the social and economic consequences of ill health (p. 256).

The PHLS, in a publication by Thomas (2004), lists specific skills associated with each ethical principle. Both the principles and skills emphasize that special attention should be paid to and action taken on behalf of vulnerable populations and the disenfranchised (PHLS, 2002; Thomas, 2004). Advocacy on behalf of vulnerable populations should be undertaken in concert with empowering the community to help themselves (Coughlin, 2006; PHLS, 2002; Thomas, 2004). Health is situated in the context of environment, education, income, and so on, and the causes of health disparities are both multilevel and multifactorial (Braveman & Gruskin, 2003). Kass (2001) proposes that public health likely has an ethical obligation to intervene on these variables that are indirectly tied to health in order to reduce the incidence of disease.

1.3 PURPOSE OF THE THESIS

1.3.1 Participation in clinical services and health research

The literature shows low levels of participation in clinical services and health research among African Americans, the elderly, and minority elders (Hall, 1999; Stallings, Ford, Simpson, Fouad, Jernigan, Trauth, et al., 2000; Gavaghan, 1995; Hutchins, 1999). Eliminating health disparities experienced by African American elders is unlikely to occur without increasing their participation in health research and health improvement programs as well as regular visits with a health care provider. Strikingly, some research has shown that the previously discussed health disparities among minority elders are present despite participation in Medicare, universal health care for Americans aged 65 years and older (Chen, et al., 2005). This thesis explores why elderly African Americans do not participate more frequently in health research and programming and what can be done to improve outreach and recruitment, with the ultimate goal of helping to eliminate health disparities. Factors impeding participation and possible solutions will be examined through the lens of systems theory.

1.3.2 Systems theory

As has been previously mentioned by several sources cited thus far in this thesis, the determinants of health are multilevel and multifactorial. Understanding the many possible determinants of health is one of the skills for the ethical practice of public health put forth by Thomas for the PHLS (2004). Theories that consider multiple levels and

sources of problems and solutions are systems theories. The systems theory most familiar to public health practitioners is likely the social ecological model. Bronfenbrenner (1979) initiated the major application of ecology to human development. The social ecological model considers many levels of health determinants: intra-personal, interpersonal, group (e.g. family, school, work), community, environmental, government and policy, and so on. However, more recently, systems theories initially associated with business management, physics, and engineering have begun to diffuse into the field of public health. Systems thinking is becoming more valued as a skill for the public health practitioner. In fact, the Association of Schools of Public Health (ASPH) includes systems thinking as one of its interdisciplinary / cross-cutting competencies for Master's of Public Health (MPH) students.

Systems thinking provides a vastly different framework for considering complex problems than the typical reductionist view. Instead of considering a system as the sum of its component parts, systems theories look at the gestalt. Systems are more than the sum of their parts. This will be described in more detail in the background section of this paper. Suffice it to say here that participation in health services and health research takes place in the context of a system composed of many influential elements, so systems thinking may provide insights regarding African American elders' participation in these activities.

1.3.3 Scope of thesis and research questions

This thesis (1) reviews the literature regarding outreach to and recruitment of African American elders; (2) reviews the literature regarding systems theories, providing a basic

general understanding of them; (3) discusses the application of systems theories to public health; (4) provides examples of outreach and recruitment issues from the community organization in which I completed my practicum; and (5) applies systems thinking to both the literature and the community practicum example of outreach and recruitment of African American elderly. The ultimate purpose of this thesis is to examine the utility of systems theories to explain outreach and recruitment of this potentially hard-to-recruit population.

2.0 BACKGROUND

2.1 RESEARCH PARTICIPATION, OUTREACH, AND RECRUITMENT AMONG MINORITIES AND MINORITY ELDERS

2.1.1 Barriers to clinical service, health improvement, and health research participation

2.1.1.1 Individual level barriers

Individual concerns such as lack of transportation, distance from the research center or clinic, need for child care or other family responsibilities (for elders this may include caregiving responsibilities for an ill spouse) can all act as barriers to research participation (Alvarez, Vasquez, Mayorga, Feaster, & Mitrani, 2006; Wendler, et al., 2006; Chinn, White, Howel, Harland, & Drinkwater, 2006). Many barriers to participating in health improvement programs such as exercise and healthy eating regimens are identified in the literature as well. Chronic health conditions, pain, “laziness” (the term used by participants in semi-structured interviews), shortness of breath, and desire not to impose on other family members can keep African Americans and the elderly from participating in health improvement programs (Belza, Walwick, Shiu-Thornton, Schwartz, Taylor, & LoGerfo, 2004; Resnick, Vogel, & Luisi, 2006).

Specifically for minority elders, they may be afraid of being surrounded by young people instead of age-matched peers or uncomfortable that no one else looks like them in a group exercise setting (Belza, et al., 2004). Elders' fear of leaving their houses or apartments due to concerns about crime is another often reported barrier (Belza, et al., 2004; Resnick, et al., 2006; Levkoff & Sanchez, 2003). In addition, low self-esteem and low motivation for self care were reported by Belza and colleagues as barriers to participation.

2.1.1.2 Interpersonal level barriers

Family responsibilities can make it difficult for people to take part in health promotion research. Chinn and colleagues (2006) report that in their Newcastle Exercise Project (NEP)¹, non-participants and those lost to follow-up were more likely adult caregivers. If potential participants are caring for children, they may not be able to participate in research unless childcare is provided (Wendler, et al., 2006). In some cases, multiple family members are consulted during the decision for an elder to take part in a study, and this can act as a barrier to participation (Levkoff & Sanchez, 2003).

2.1.1.3 Organizational level barriers

Many organizational level barriers to health improvement programming and research are discussed in the literature. If recruitment gatekeepers at community organizations with which researchers partner do not have a good opinion of research, this can act as a barrier to minority elders participating in research (Levkoff & Sanchez,

¹ This was a randomized controlled trial of interventions promoting physical activity in Newcastle upon Tyne in the United Kingdom.

2003). The lack of time and resources of these community organizations can also act as barriers to participation (Levkoff & Sanchez, 2003; McCallum & Arlien, 2006).

Barriers among the research team itself and within and among universities have been reported in the literature. In their description of the recruitment experiences of the Exploratory Centers for Minority Aging and Health Promotion (MAHP), Levkoff & Sanchez (2003) found that the multidisciplinary and multicultural nature of the staff caused communication difficulties that were felt to harm recruitment. In addition, the authors state that within the same university there was competition for the same potential participants. This unfortunately left the community agency confused and unwilling to partner for recruitment and outreach purposes. Finally within the MAHP there was competition between different universities which was felt to diminish recruitment.

With regard to clinical trials of medications, stringent inclusion / exclusion criteria can cause difficulty with recruitment (Cassidy, Baird, & Sheikh, 2001). For instance, in a trial of Zoloft in elderly patients, out of 210 phone screening interviews, 57 were too young, 32 had an exclusionary psychiatric diagnosis, 31 had an unknown exclusionary diagnosis, and 7 had an exclusionary medical diagnosis. Others who completed the screening interview refused to participate or were considered false leads by the investigators. Out of 26 in person screening appointments generated by the telephone screenings, 3 were screen failures.

2.1.1.4 Community level barriers

Barriers to research and health improvement program participation exist on the community level. The odds of not participating in a walking program for African American women were greatly increased by living in a high poverty area (Wilbur, et al.,

2006). Similarly, non-participants in the NEP were more likely from the least affluent areas of Newcastle (Chinn, et al., 2006).

2.1.1.5 Other system level barriers

Numerous external and system level factors act as barriers to clinical service and health research participation. Perhaps primary among barriers for African Americans is distrust of the medical and research system. Some disagreement exists in the literature regarding the role of the Tuskegee Syphilis experiments in African Americans' distrust of the medical system. For example, Brown and Topcu (2003) found in a community survey that more African Americans than whites knew about Tuskegee, but this did not change their stated willingness to participate in a hypothetical clinical trial. Regardless of the particular reason, distrust remains a key barrier. In a national telephone survey of African American and white respondents, the level of distrust was higher for African Americans, even after controlling for other socioeconomic factors (Corbie-Smith, Thomas, & St. George, 2002). African Americans were more likely to believe that doctors would expose them to unnecessary risks, not fully inform them about the research, or enroll them into research without their consent.

Despite previously cited studies in which investigators have found lower levels of research participation among African Americans, the reality of the situation is not so cut and dry. Wendler and colleagues (2006) undertook a systematic review of both intervention and non-intervention research looking especially at consent rates by ethnicity. They conducted the review because many researchers assume that minorities are underrepresented in research studies due to lack of willingness to participate. The authors differentiate between potential subjects who were eligible, those who were

invited to participate, and those who consented. They found no existing research regarding consent rates. The investigators found 20 applicable studies, based mostly in the U.S., across a range of health conditions and risks inherent in the studies. Overall, Wendler, et al. found no differences in consent rates by ethnicity, indicating that if minorities were eligible and invited to participate, they did consent. However, when differences were found, the investigators report that frequently minorities were more willing to consent. The investigators did find a difference in the number of minorities invited to participate in the studies compared with the expected number based on the proportional make up of the population. Writing in a commentary on the Wendler, et al. review, Sheikh (2006) argued that many investigators place the onus for study participation on minorities themselves, feeling that when there is low minority participation it is because minorities do not understand the importance of research and their participation in it. Sheikh suggests that more minorities need to be invited to participate in research by the people in positions of power. Given Wendler et al.'s findings, minorities may be quite likely to consent if they are invited to take part.

Other system-level barriers to clinical care and participation in health improvement programs include income, access to care, and type of insurance (Chen, et al., 2005). In their analysis of data from the California Health Interview Survey (CHIS), Chen and colleagues (2005) found that respondents aged 65 and older who had Medicare plus Medicaid were less likely to get preventive health screenings. Those who had Medicare plus other insurance were more likely to get screenings (Chen et al., 2005). Belza and colleagues (2004) found through focus groups with ethnically diverse elders that poor weather, programs taking place late in the day, safety concerns, and high

exercise program costs can also discourage seniors from participating in health programming.

Another difficulty with ethnic minority health research is suggested by a review (Yancey, Kumanyika, Ponce, McCarthy, Fielding, Leslie, et al., 2004) of studies of obesity and overweight interventions for US minorities. First, the authors report that no conclusions could be drawn regarding efficacy of the interventions because outcomes were seldom reported or the sustained effects of the interventions were not significant. Second, the investigators found that only 1/3 of the studies in their review showed up in electronic databases; findings from studies with ethnic minorities are poorly disseminated (Yancey, et al., 2004). This can act as a barrier if it causes research participants to feel like they are being used solely for research purposes, and never hear any of the overall study results.

Finally, the university and research staff may be viewed as elitist, and purely interested in getting bodies for research; they may be viewed as having no actual concern for ethnic minorities, and this can act as a barrier to recruitment (Levkoff & Sanchez, 2003).

2.1.2 Facilitators of clinical service, health improvement, and health research participation

2.1.2.1 Individual level facilitators

On an individual level, various participation facilitators are reported in the literature. For instance, several authors report the use of small incentives to encourage participation (Resnick, et al., 2006; Reed, et al., 2003; Levkoff & Sanchez, 2003).

Personal opinions regarding the positive outcomes of exercise can encourage participation in exercise programs. In a series of focus groups conducted with ethnically diverse older adults, many participants reported the opinions that physical activity promotes good health and helps ameliorate chronic health conditions (Belza, et al., 2004). In follow-up focus groups conducted after a 12 week exercise program intervention for minority adults, Resnick, et al. (2006) report that participants cited the physical benefits of exercise as motivating them as well. The emotional benefits of exercise were cited by focus group participants in both the Belza, et al. (2004) and Resnick, et al. (2006) studies. Additional individual level facilitators of participation in exercise programming include the use of exercise as meditation and a way to be out in nature (Belza, et al., 2004); accomplishing goals such as weight loss, gaining confidence in the proper performance of exercises, trying new activities, and learning new information encourage ongoing participation (Resnick, et al., 2006).

Developing the habit of exercise improves participation in this type of programming (Belza, et al., 2004). In a study of diurnal cortisol levels of caregivers vs. non-caregivers, important individual level participation facilitators included caregivers getting the chance to discuss some of their stressful issues and receiving referrals to community resources if requested (McCallum & Arlien, 2006). Some studies made an effort to allow for home visits, conduct appointments at other convenient sites such as churches, or arrange for transportation, all of which were seen as facilitating participation (Levkoff & Sanchez, 2003; Reed, et al., 2003). Income acts as a facilitator of participation for whites according to Brown & Topcu's (2003) community survey. The investigators used a conceptual framework combining the theory of reasoned action

(Ajzen & Fishbein, 1980) and the health behavior model (Andersen, 1995). They state that income is an “enabling factor” which is one factor influencing “behavioral intention.” However, the authors did not clarify why income may be an enabling factor only for whites and not blacks.

2.1.2.2 Interpersonal level facilitators

Interpersonal level factors play an important role in encouraging participation. Elders involved in health improvement research and programming enjoy the individualized attention paid to them by exercise staff (Resnick, et al., 2006), and research staff at the Centers for Minority Aging and Health Promotion made it a point to exhibit true concern for potential participants referred to them (Levkoff & Sanchez, 2003).. One common finding across two studies using focus group methodology was the social nature of exercise acting as a facilitator (Belza, et al., 2004; Resnick, et al., 2006). Specifically, focus group participants reported the idea of friends supporting each other, the social nature of the programming, exercising in a group, discussing health together, incorporating exercise as part of your social life, and the social components of encouragement, accountability, and interaction as key motivators to participate in exercise programs (Belza, et al., 2004; Resnick, et al., 2006). Exercising in a group, it seems, provided an external force which was needed to encourage participation (Resnick, et al., 2006). The provision of educational information regarding how and why to perform certain exercises and how to effectively deal with pain has also been cited as a facilitator to participation in exercise programming (Resnick, et al., 2006).

In terms of specific recruitment strategies, social network recruiting proved to be very effective in the Women’s Walking Program (WWP) reported by Wilbur and

colleagues (2006). This method of recruitment was not specifically planned for and cultivated, but half of the 696 women expressing at least initial interest in participation reported hearing about the program from a friend, family member, and the like. Word of mouth was a planned outreach strategy used in the African American Wellness Village (McKeever, et al., 2006).

2.1.2.3 Organizational level facilitators

Several participation facilitators at the organizational level are reported in the literature. Decisions by the research or health promotion organization regarding referral sources and research staff are reported in the as facilitators of participation. For example, several studies have collaborated with churches and / or used pastors to assist in the recruitment of church members (Reed, et al., 2003; Levkoff & Sanchez., 2003). A doctor's referral can be a very effective recruitment method (Arean, et al., 2003; Etkin, et al., 2006). In fact, in one study of an intervention for geriatric mental health, minorities responded only to a doctor's referral and not to other recruitment methods (Arean, et al., 2003). Site coordinators and other staff at community agencies acted as referral sources for some studies, and this was especially helpful when site staff identified potentially interested and / or eligible participants (Etkin, et al., 2006; Levkoff & Sanchez, 2003).

Staff employed directly by research studies could act as facilitators in several ways. Arean, et al. (2003) report that face to face recruitment by study staff was the second most effective recruitment strategy in one study of an intervention for geriatric mental health. Several studies utilized study staff of a similar background to the potential participants being recruited (Wilbur, et al., 2006; Levkoff & Sanchez, 2003; Abernethy, et al., 2005). Study staff acted as facilitators when they presented a positive view of

research and reassured participants regarding confidentiality (Levkoff & Sanchez, 2003). In the WWP, two research staff members sat on other community organization boards, and thus were able to identify upcoming health fairs and other events of interest for outreach (Wilbur, et al., 2006). At Duke University, which houses one of the Exploratory Centers for Minority Aging and Health Promotion, the presence of minority Principal Investigators was seen as a way to encourage minority research participation (Levkoff & Sanchez, 2003).

Many of the organizational level facilitators reported in the literature deal with what the research organization can provide to community organizations helping with outreach and recruitment efforts. Keeping these recruitment gatekeepers up to date regarding the research and minimizing the extra work that recruitment requires of them are important facilitators (Levkoff & Sanchez, 2003). Several studies provided or sponsored educational lectures for the community agencies, sometimes in the form of lunch and learn sessions (McCallum & Arlien, 2006; Alvarez, et al., 2006). Community organizations also saw a benefit from partnering with the research institution due to having an opportunity to network with other community organizations and finding a potential future partner for community initiated research (Alvarez, et al., 2006).

Other important organizational level participation facilitators include the dissemination of study results to participants via newsletters and maintaining a flexible schedule for appointments, including night and weekend availability (Levkoff & Sanchez, 2003; McCallum & Arlien, 2006; Alvarez, et al., 2006).

2.1.2.4 Community level facilitators

Many participation facilitators on the community level are reported in the literature. Interestingly, community can be an outcome of health improvement programming that encourages future participation. McKeever and colleagues (2006) report on the African American Wellness Village held annually in Portland, Oregon. This event combines health screenings, demonstrations, and entertainment. Participants state that they enjoy the feeling of community that has developed through this annual event.

Many authors reporting on the process of recruitment and outreach to encourage participation in clinical services, health improvement programming, and health research state the importance of community (Lee, 2005; Wilbur, McDevitt, Wang, Dancy, Briller, Ingram, et al., 2006; McKeever, Koroloff, & Faddis, 2006; Levkoff & Sanchez, 2003; McCallum & Arlien, 2006; Reed, Foley, Hatch, & Murran, 2003; Areal, Alvidrez, Nery, Estes, & Linkins, 2003). When the African American Wellness Village was first being developed, community partnerships were formed (McKeever, Koroloff, & Faddis, 2006). Recruitment was effective because trusted African American doctors and community partners encouraged African American participation in health screenings and the like at the village. The trust was already inherent in the community, and this is why a sense of community is so important in community-based research. Lee (2005) found that community-based approaches are especially effective with African Americans and proposes that population member involvement and community collaboration are key to developing effective interventions. Some studies have found that the use of a community advisory board was integral to the success of their outreach and recruitment efforts

(Wilbur, et al., 2006; Levkoff & Sanchez, 2003; Reed, et al., 2003; Arian, et al., 2003). In addition, Reed and colleagues (2003) found that the diversity of their board allowed them to successfully partner with a variety of churches. Through feedback from various board members, appropriate ways to approach different churches were determined. Although all investigators do not form community advisory boards or utilize those already in existence, there are other ways to gather community input. Wilbur, et al. (2006) and McCallum & Arlien (2006) used focus groups with community members to develop effective recruitment and outreach plans.

Community locations offer effective recruitment venues. Schools, churches, worksites, exercise program venues, senior centers, and retirement communities are just some of the types of sites reported in the literature (Wilbur, et al., 2006; Etkin, et al., 2006; McKeever, et al., 2006). Wilbur and colleagues (2006) found that community presentations and brochure distribution were their most effective recruitment methods.

A creative community level facilitator of participation is suggested by Fritsch and colleagues (2006). The University Memory and Aging Center of the University Hospitals of Cleveland and Case Western Reserve University sponsored a playwriting contest. The play was required to deal with Alzheimer's disease (AD) in African Americans. Judges selected the top plays to be performed. Talk-back sessions with research staff knowledgeable about AD were held after the performances. In the five years prior to the production of the plays, 16.5% of the recruited research participants were African American. In the six months after the play, 36.4% of the recruited participants were African American with 16 of 32 minorities recruited reporting they had seen the play.

2.1.2.5 Other system level facilitators

Perceptions and cultural beliefs offer another source of potential facilitators of participation. Both culturally sensitive recruitment and culturally tailored health programming have been used to good effect (McKeever, et al., 2006; Kiger, 2003). Abernethy, et al. (2005) emphasized cultural and religious beliefs that encouraged following through on prostate cancer screening. Finally, McCallum & Arlien (2006) state that if the university involved in the research is perceived as a credible and trusted source for information, this can assist with outreach and recruitment.

2.2 RECRUITMENT MODELS

This section provides a basic overview of some of the models of recruitment found in the literature.

2.2.1 Matching model

The matching model of recruitment was utilized both in the MAHP program described by Levkoff and Sanchez (2003) and the study determining the difference in diurnal cortisol levels between caregiving and non-caregiving adults described by McCallum and Arlien (2006). According to Levkoff and Sanchez (2003), with the matching model, both the investigator and the potential participant are viewed as having their own perspectives regarding the research. These perspectives are based on multiple influences including agencies they may work for, culture, and so on. When these perspectives match,

recruitment is more likely to be successful. This model emphasizes consideration of research enablers and barriers occurring at three levels: the macro level, which includes system level considerations, the mediator level, which includes factors dealing with gatekeepers of research access and moving from individual level to macro level, and the individual level, which includes factors specific to the individual potential research participant (Levkoff & Sanchez, 2003). These three levels of enablers and barriers interact dynamically (Levkoff & Sanchez, 2003). The use of this model was felt by the authors to be successful insofar as it allowed the consideration of enablers and barriers; the use of focus groups allowed for early discussion and preparation to address the potential barriers to recruitment (McCallum & Arlien, 2006).

2.2.2 Consumer-centered models

Arean, et al. (2003) detail a comparison of consumer-centered models of recruitment with traditional models. Consumer-centered models utilize four main principles: (1) community advising of research team (usually as a community advisory board); (2) composing the staff to be ethnically similar to the community/participants; (3) anticipating and responding to participant burden; and (4) providing feedback to the community (Arean, et al., 2003). Arean and colleagues (2003) compared two studies of geriatric mental health, with one using a consumer-centered model of recruitment and the other using standard methods. In the study using traditional methods (doctor and self-referral), the rate of agreement to participate was 44% compared with a 68% agreement rate in the study using the consumer-centered model. However, specifically with regard to elderly ethnic minorities, the consumer-centered methods resulted in a greater

proportion who were willing to be approached about participating, but not a greater proportion who were willing to participate (Arean, et al., 2003).

2.2.3 Community organization engagement model

Alvarez and colleagues (2006) describe a recruitment model of engaging community organizations for referrals into a research study. The purpose of this study was to learn more about medication adherence and substance abuse in HIV positive women. The investigators identified many community organizations with which they thought they might partner. These included drug treatment clinics, community hospitals, health education centers, drug treatment centers, and so on. Research staff maintained a log of the process of engaging these organizations. The log was kept as a flow chart in order to allow for a visual representation of the process. First, contact was made with someone at a high level of responsibility within the community organization, and the study was described. Then, if the contact person was agreeable, a follow-up presentation was made to staff or clients. The investigators also received qualitative feedback from organization staff which they implemented into their engagement approach. The community organization staff suggested that the investigators must be seen as more than simply takers (Alvarez, et al., 2006). So, the research staff provided educational sessions for community agencies and volunteered for the community agencies. At the time of publication, the investigators reported recruiting 50 of the desired 176 participants.

2.2.4 Professional and volunteer staffing model

Kiger (2003) describes outreach practices at the Center for Healthy Aging (CHA) in Santa Monica, CA. The goal of this organization's cancer program is to screen 1000 low income, uninsured, or underinsured women for breast and cervical cancer. The primary focus is on African American and Latino women. Volunteers were supervised by professionals and used to help with outreach in three different culturally tailored programs (Kiger, 2003). One program is "Tell a Friend" (TAF) in which African American women tell their friends about cancer screening. The second program is "The Witness Project" which focuses on the recruitment of African American women with methods incorporating spiritual and faith components. "Promatora" (Spanish for "health educator") is the third program in which Spanish speaking lay health educators outreach to community members. Some of the volunteers working at the Santa Monica CHA were women who had received services at the clinic. These services were provided free of charge, and some of the women saw volunteering as a good way to pay the clinic back for what they had received (Kiger, 2003).

The overarching characteristics of the professional and volunteer staffing model are: 1) lay people are trained to outreach to the community and supervised by professionals; 2) outreach is language and culture appropriate; 3) education is provided to the community members; 4) outreach may be provided by survivors of cancer; and 5) the community members are offered the chance to participate in the CHA program.

2.2.5 PEN-3 model

The PEN-3 model, a model of public health planning, was used in a Prostate Cancer Screening (PCS) study of African American men (Abernethy, et al., 2005). Airhihenbuwa (1993) developed the PEN-3 model, designed to allow for culturally appropriate health promotion planning. The model has three components. First, health education considers decisions based on roles, and are within the contexts of: (1) person, (2) extended family, and (3) neighborhood. Second is the educational diagnosis of health behavior. Here, factors that influence health actions are determined. These factors are influenced by existing health behavior theories along with considerations of culture (Airhihenbuwa, 1993). The factors are again divided into three types: (1) perceptions, or knowledge, attitudes, and beliefs affecting behavior change; (2) enablers, factors that may either enhance or be barriers to change; and (3) nurturers, people who influence enablers and perceptions (Airhihenbuwa, 1993). Third, the cultural appropriateness of health behavior is determined. This is categorized as: (1) positive behaviors, cultural beliefs that encourage good health behavior; (2) existential behaviors, which have no harmful health consequences and thus are not targeted for change; and (3) negative behaviors, known to be harmful to health and thus are targeted for change within the cultural context.

In the PCS study, the PEN-3 model guided recruitment considerations. For example, in order to encourage men to be screened for prostate cancer, investigators had to counter the negative health behavior of not going for screenings and not going to the doctor within the cultural context of fatalism as a cultural and religious belief (Abernethy, et al., 2005). Many churchgoing African Americans feel that if it is their time to go, then

that is fine because it's God's plan (Abernethy, et al., 2005). The investigators explored this issue specifically and were able to find some pastors who provided another interpretation—there is a “balm in Gilead” meaning that God has provided the means to take care of health concerns (Abernethy, et al., 2005). The PCS study had a proposed recruitment of 450 and it successfully recruited 655 men.

2.3 SYSTEMS THEORY

In this section, the thesis turns from facilitators, barriers, and models of recruitment to systems theory. Systems theory has been a prevailing framework in many fields such as physics, engineering, and business management since the mid to late 1900's. More recently, systems theory has begun to influence other fields such as medicine and public health. Many public health practitioners are familiar with the social ecological model, but other systems theories are now being incorporated into public health. This section provides an overview of what the literature has to say regarding systems theory that may be relevant to community outreach and recruitment methods in public health.

2.3.1 Historical context of systems theory

During the 1600's, the philosopher René Descartes described the mind and body as fundamentally different aspects of human beings, an idea known as dualism. This conception of the mind and body being separate components persists in western medicine today with the separation of medicine and psychiatry/psychology. Skyttner (2005) states

that dichotomies such as mind and body, man and nature, and the like became pervasive at that time. At the same time, the scientific world was removing itself from the religious world. In order to separate religion and philosophy from the church, impartiality and objectivity became important qualities of science (Skyttner, 2005).

During the 1700's, the machine became the overarching metaphor for science (Zimmerman, Lindberg, & Plsek, 1998; Skyttner, 2005). A machine may be disassembled and each part studied individually. The function of each part is known, and the sum of these structures and functions gives the structure and function of the machine. The machine metaphor illustrates both the notion of reductionism² and determinism³. All action in the universe was seen to obey deterministic natural laws such as the laws of physics. An important assumption in this scientific, reductionist view of the world is the irrelevance of the environment (Skyttner, 2005). A machine will produce the same output in a laboratory as it will in a home.

In the 1800's, Comte, an important figure in the field of sociology, put forth the basic principles of positivism.⁴ Thus we have a scientific approach in which the truths of the universe are knowable by observation; scientists are objective; environment is irrelevant; knowledge of the full machine is given by the knowledge of its component parts; effects are determined by causes; and quantitative data are preferred.

Skyttner (2005) explains that, in the 1900's, quantum mechanics introduces the fork in the road away from this previous notion of science. Determinism is questioned

² By understanding each machine part separately, we understand the whole machine (Zimmerman, et al., 1998).

³ Effects are causally determined, and "to every action there is a reaction," (Skyttner, 2005, p. 12).

⁴ "An approach to social science that combines a deductive approach with precise measurement of quantitative data so researchers can discover and confirm causal laws that will permit predictions about human behavior," (Neuman, 2003, p. 541).

when certain properties of atoms are discovered. For example, atomic systems have multiple properties, and scientists found that if one property was observed, it was impossible to measure and know the other property at the same time. Thus when some event acts on an atom the outcome is indeterminate. Scientists dealing in quantum mechanics deal in the probabilities of certain atomic outcomes instead of absolutes (Skyttner, 2005). Skyttner (2005) argues that this calls into question whether there is an ultimate truth or whether “truth” is a construction of the observer. This exposes the additional complication of not allowing for a thorough knowledge of the component parts of an atomic system, and this keeps us from knowing the whole system. Finally, atomic particles behave in ways that cannot be predicted. Sometimes their behaviors are “genuinely spontaneous” (Skyttner, 2005). This calls the deterministic, positivist view into question.

2.3.2 What is systems theory?

First of all, it is important to point out that there are a number of systems theories. Refer to Table 1 for a sample of various theories and associated authors or practitioners. Systems theories are intended to be cross-disciplinary in nature. They integrate disciplines and attempt to find a common language and solutions to problems that are common across specialized domains of knowledge. Regarding the scientists who first worked with systems theories, Skyttner (2005) states, “They wanted to link together the many splintered disciplines with a **law of laws** applicable to them all”⁵ (p. 39). In

⁵ Emphasis in original.

particular, these systems theories are models, and some of them do have associated computational modeling techniques associated with them via software programs. Sterman (2006) states that this kind of modeling is simulation, which can be accomplished through physical models, role-playing, or virtual worlds, though the problems dealt with in complex systems are so unwieldy for real world modeling that virtual modeling will usually be required. Virtual modeling allows us not only to handle very complex problems in which numerous agents and issues are involved, but it also allows us to experiment with multiple initial conditions, test situations that would be unethical in the real world, and stop action in the middle of the simulation to reflect on what is happening (Sterman, 2006). Sterman (2006) and Homer and Hirsch (2006) state that one systems theory, system dynamics, provides virtual modeling techniques that can be used to simulate public health problems. A complete discussion of virtual simulation is beyond the scope of this thesis; however, interested parties may consult Leonard and Beer (1994) and Sterman (2006).

Table 1. A sample of systems theories (adapted from Leonard & Beer, 1994, and Skyttner, 2005)

Theory name	Affiliated Author or Practitioner
Living Systems Theory (LST)	J.G. Miller & colleagues
Operations Research (OR)	Ackoff, Blackett
Socio-Technical Systems (STS)	Trist, Bamforth, Emory
Soft Systems Methodology (SSM)	Checkland
System Dynamics	Forrester
Total Quality Management (TQM)	Deming, Juran
Viable Systems Model (VSM)	Beer
Hierarchy of Systems Complexity	Boulding
Gaia Hypothesis	Lovelock, Margulis
Nōosphere	Chardin
Geopolitic Systems Model	Taylor
General Systems Problem Solver (GSPS)	Klir
Natural Systems	Laszlo
Quantal System	Cook
Systems Taxonomy	Jordan
Family Systems Theory	Bowen, Kerr
Stratified Systems Theory (SST)	Jaques

2.3.3 Complex adaptive systems

One field that has emerged from the evolution of systems theories is complexity science or complex adaptive systems (CAS). Complexity science is another umbrella term for a variety of theories which fall underneath it. “It is the study of CASs,” (Zimmerman, et al., 1998, p. 5). Complexity science applies biological concepts and metaphors to living systems (Zimmerman, et al., 1998). These are natural or human systems, and they evolve over time, self-organize, and display emergent behavior⁶ (Zimmerman, et al., 1998). Skyttner (2005) states, “Complexity theory tries to describe how complicated rules

⁶ Behaviors that should not be outcomes based solely on the starting input of the system. This displays the synergistic nature of the CAS in which the system is more than the sum of its component parts. Emergent behaviors make CASs unpredictable.

sometimes produce simple and organized behaviour, e.g. the ability of living systems to become ever more organized” (p. 45). Zimmerman and colleagues (1998) provide the following definition of CAS:

“Complex” implies diversity—a great number of connections between a wide variety of elements. “Adaptive” suggests the capacity to alter or change—the ability to learn from experience. A “system” is a set of connected or interdependent things. The “things” in a CAS are independent agents. An agent may be a person, a molecule, a species or an organization, among many others (p. 8).

Refer to Table 2 for a listing of the characteristics of CASs.

Frequently with CASs, a few simple rules can produce very complicated behavior (Zimmerman, et al., 1998; Miller & Page, 2007). Zimmerman and colleagues (1998) provide the example of a computer simulation called “Boids.” If three simple rules are programmed into the system, the boids will exhibit flocking behavior that closely approximates how flocks of birds fly together and navigate around obstacles, a highly complex system behavior.

Table 2. Characteristics of a CAS (adapted from Zimmerman, et al., 1998; Plsek & Greenhalgh, 2001; and Miller & Page, 2007)

- ~Is composed of independent agents
- ~Agents act on local knowledge
- ~No central decision maker or authority exists; control is distributed
- ~Behavior is goal oriented
- ~Is composed of other CASs
- ~Is made up of diverse elements
- ~Properties emerge from the system; the system is unpredictable
- ~Creativity emerges from the system
- ~Is a nonlinear system; input and output are not related in a linear fashion
- ~Learns and evolves
- ~Is history dependent
- ~Exists in an area between predictable stability and complete anarchy, on the edge of chaos
- ~Paradox is inherent
- ~Is drawn to attractors⁷
- ~Simple rules can lead to complex behavior
- ~Stocks⁸ and flows⁹ exist in the system
- ~Feedback loops¹⁰ exist in the system

Stacey (1996) developed the agreement and certainty matrix primarily to assist managers of organizations with decisions regarding leadership style under various conditions (see Figure 1). But for the purposes of this thesis, it is also instructive to visualize where on the matrix CASs exist given varying systems that may be possible. In other words, the matrix can help us to determine whether a particular system is a CAS. Certainty is indicative of the level of confidence regarding a given outcome. High certainty is present in known causal relationships (Zimmerman, et al., 1998). For

⁷ "...a pattern or area that draws the energy of the system to it. It is a boundary of behavior for the system," (Zimmerman, et al., 1998, p. 12).

⁸ Taken from System Dynamics. Refers to the fact that things such as materials, and energy accumulate in a system

⁹ Taken from System Dynamics. Flow affects stocks in the system. Materials and energy flow into and out of the system affecting the stock.

¹⁰ Taken from System Dynamics. Outcomes of decisions are fed back into the system and may reinforce or dampen actions.

instance, based on past experience, I know that if I turn on my air conditioner, my house will get cooler. Therefore I am highly certain that if I turn on my air conditioner later tonight, my house will again get cooler.

Agreement is based on agreement among system agents regarding future action (Zimmerman, et al., 1998). If five other housemates of mine agree that the temperature in the house is too hot, then agreement is high. However, if two of us think it is too cold, two of us think it is just right, and two of us think it is too hot, then agreement is low. As illustrated in Figure 1, when certainty and agreement are both high, the situation is simple. Choices are defined, and decision-making can proceed rationally (Zimmerman, et al., 1998). At the other extreme, when certainty and agreement are both low, we have chaos or anarchy. In the area between simple, rational decision-making and anarchy this is what Zimmerman et al. (1998) refer to as the edge of chaos and Stacey (1996) calls the zone of complexity. This is where CASs operate.

The Stacey matrix is important in this thesis because it can help to determine if community-based approaches to recruitment are CASs (see section 5.2). However, it is also important to realize that the complexity science approach is not always the best approach. The approach that is best for a given problem will be determined by the level of certainty and agreement. A good health related example of this is provided by Brown (2007) who states that a ruptured appendix is best handled by the medical model of disease. There is high certainty and high agreement in this instance and removing the appendix will resolve the patient's illness. A complexity science approach is not required.

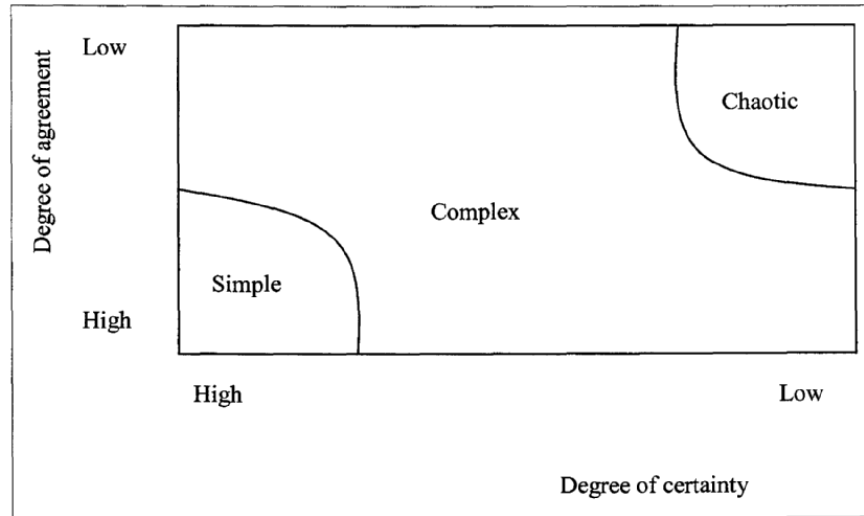


Figure 1. The Stacey agreement and certainty matrix. Adapted from Plsek & Greenhalgh, 2001, and based on Stacey, 1996.

2.3.4 Systems and health

Systems theories, especially CAS and System Dynamics, are diffusing into the fields of medicine and public health. This application is relatively new, and the typical approach to health in the United States has been the medical model of disease, a reductionist view in which causality is known. The solution to illness in this model is to remove or medicate the diseased component of the body.

However, some human health issues are likely not best resolved with only the solutions offered by the medical model. Brown (2007) describes a CAS view of chronic pain. CASs have also been applied to health care systems, health care organizational management, health professional education, glycemic control in diabetes, and health promotion (Plsek & Greenhalgh, 2001; Plsek & Wilson, 2001; Fraser & Greenhalgh, 2001; Wilson & Holt, 2001). Zimmerman and colleagues (1998) state that community

health, being so context-dependent, is ripe for a complexity science-based approach. Community health is dependent upon a complex interplay of agents at multiple levels: individual biology and health behaviors, family situation and health practices, community norms, environmental factors such as air and water pollutants and the availability of recreational space, and policy and government factors such as state children's health insurance plans. Each community has a varying set of resources and strengths as well which will affect health. The resources and strengths of a community can be thought of as stocks in the system, and the stocks will be affected by the flow of additional resources in or out of the community.

3.0 METHODS

For the purposes of this thesis a literature review was conducted and existing minutes from meetings held in a community organization were reviewed.

3.1 LITERATURE REVIEW PLAN

The plan for this literature review was developed in consultation with a medical librarian within the Health Sciences Library System at the University of Pittsburgh. The purpose of the literature review is to provide a general sense of the state of the literature regarding outreach and recruitment of African American elders, general background on systems theories, and information regarding the application of systems theories to public health, especially as it relates to recruitment. Ovid was used to search MEDLINE and PsycINFO for relevant literature. Search terms were mapped onto non-MeSH subject headings and exploded, as well as being searched for as keywords. The terms falling under a specific topic area, e.g., the terms associated with outreach and recruitment, were then connected with the Boolean operator “or” to find articles associated with any of the subject headings used. Finally, the results of these searches were combined by Ovid and reviewed manually. Once pertinent articles were selected, their reference lists were reviewed for additional resources.

For some topics, e.g., systems theories in public health, the Internet was also searched.

3.1.1 Literature search regarding outreach and recruitment of African American elders

In order to find articles associated with outreach and recruitment, the following search terms were used: “outreach”, “recruitment”, and “patient selection”. The setting was narrowed to research and clinical care via these search terms: “community health services”, “health education”, “health promotion”, “education, medical”, “research”, and “clinical trials”. The subject heading used to capture articles regarding the elderly was “aged”. Finally, articles relating to African Americans were found with the following subject headings: “African American”, “ethnic groups”, and “minority groups”.

3.1.2 Literature search regarding systems theory

The literature was searched for both general systems theory information and systems theory information relevant to public health. In Ovid, the following search terms were used: “systems theory”, “complex adaptive systems”, “social environment”, and “social ecology”.

Further information regarding systems theories in public health was found on the Internet at the Association of Schools of Public Health (ASPH) website. Systems thinking is listed as an interdisciplinary/cross-cutting competency domain for master’s of public health (MPH) students according to version 2.3 of ASPH’s MPH core competency

project (2006). The systems thinking competency is stated as, “The ability to recognized system level properties that result from dynamic interactions among human and social systems and how they affect the relationships among individuals, groups, organizations, communities, and environments” (ASPH, 2006). This document lists eleven specific systems thinking competencies such as: “Identify unintended consequences produced by changes made to a public health system”; “Explain how the contexts of gender, race, poverty, history, migration, and culture are important in the design of interventions within public health systems”; and “Analyze inter-relationships among systems that influence the quality of life of people in their communities”. The ASPH website also provides more information regarding systems in public health on one of their pages entitled, “Systems Thinking.” A more in depth definition of systems thinking is provided, authors in the field are listed, key terms used in systems theories are defined, and resources for more information regarding systems thinking are suggested.

3.2 COMMUNITY MEETINGS

Community meetings were held at Hosanna House, a community center in a low-income, predominantly African American borough bordering the City of Pittsburgh. The meetings were held in the context of my practicum, a requirement for my MPH degree. The department at the Graduate School of Public Health (GSPH) within which I study (Behavioral and Community Health Sciences [BCHS]) has developed an ongoing partnership with Hosanna House to allow students the opportunity to interact directly

with community members, and likewise, to allow the community direct access to academia. My practicum ran from August 2006 through April 2007.

3.2.1 Meeting purpose

Hosanna House is one site for the Healthy Black Family Project (HBFP), an initiative of the Center for Minority Health (CMH) at the University of Pittsburgh's GSPH. HBFP is designed to intervene on diabetes and hypertension in predominantly African American communities around Pittsburgh. Families and individuals can join the project by filling out an application and getting a release from their doctor stating that they are healthy enough to participate in an exercise program. HBFP at Hosanna House offers a number of exercise classes; a workout area with weights, exercise machines, and a heated pool; health education classes about topics such as nutrition and cancer; and support groups for people with diabetes and for those who would like to quit smoking.

Hosanna House has historically offered services centered on youth and families. It has a nationally accredited child care center and houses a variety of external programs that have offices located within the Hosanna House building, such as Women, Infants, and Children (WIC), the Wilksburg Family Health Center, and the Allegheny Intermediate Unit/DART program. Hosanna House provides summer camp for youth ages 6-12, robotics classes, and after-school youth programming. For working aged adults there are technology and entrepreneurship courses as well as HBFP.

However, over the past few years, the need for additional programming for elders in Wilksburg has become apparent. Several high rises providing senior housing have closed. In addition, the community senior center moved outside of the Wilksburg

borough line. It was run by a local community church whose congregation was recently combined with that of another church located in an adjacent community. When these two congregations combined, the senior center moved to the new church location.

Hosanna House felt the timing was right to step in and provide programming for the Wilkinsburg seniors. Working with the community to develop senior programming was the purpose of my practicum. Multiple community meetings were held to address questions such as: 1) did the community feel there was a need for programming for senior citizens? 2) how did other providers of senior services feel about Hosanna House providing programming? 3) how could Hosanna House collaborate with existing area service providers? 4) what health conditions were of most concern to the community? 5) what programming ideas did the community have in order to address these health issues? and 6) what ideas did the community have regarding effective outreach to seniors?

3.2.2 Research

The Hosanna House community meetings regarding senior programming were originally planned and conducted for non-research purposes. They were conducted to allow Hosanna House to explore the possibility of providing programs directed at seniors. I recorded the information from the community meetings and typed minutes. Once the topic for my thesis was determined, it was apparent that the minutes could add valuable information, so an application proposing to review existing de-identified records was submitted to the University of Pittsburgh Institutional Review Board (IRB). Given that the study was (1) of minimal risk to the participants; (2) a review of existing records; and (3) using de-identified information, the study was classified by the IRB as exempt from

the Federal Policy for the Protection of Human Research Subjects. In addition, no linkage codes matching names and comments were kept, so no honest broker was needed for de-identification purposes.

3.2.2.1 Meeting participants

Over the course of multiple meetings, a variety of participants attended. Community members were predominantly from HBFP at Hosanna House. Professionals included an HBFP exercise class teacher, local senior service providers, and staff from Hosanna House. One BCHS professor and one BCHS doctoral student were present as well. A senior Hosanna House staff member facilitated the first meeting, introducing me and the idea of senior programming to the community members. Following that first meeting, I either co-facilitated the meetings with another Hosanna House staffer or facilitated them myself.

Given that these meetings were not planned as research, no particular sampling plan was developed in the research sense. However, care was taken to include area senior service providers who would be knowledgeable about Wilkinsburg seniors and whose cooperation would be beneficial. BCHS representation was also important to foster the new partnership between the school and Hosanna House, introduce the community to researchers in person, and get community input regarding research.

3.2.2.2 Study design

I reviewed the existing minutes and re-recorded the information without identifiers for the purposes of research review. The resulting data are qualitative in

nature. The data were not coded in any particular way. They are used here to add anecdotal information from the actual community setting.

4.0 RESULTS

Three community meetings were held at Hosanna House, Inc. (HHI) during my master's practicum, which ran from August 2006 through April 2007. Meetings were held on September 14, 2006, October 24, 2006, and March 1, 2007. The general purpose of these meetings was to engage the community in a participatory process of developing programming for Wilkinsburg area elders.

4.1 SEPTEMBER 14, 2006

The first meeting introduced BCHS staff to the community, and was designed to get a general feel for issues surrounding outreach to seniors and opinions regarding introductory programming and health related research being completed by a BCHS professor. In attendance were three HHI staffers, two BCHS students (one of whom was me), one BCHS professor, one representative from each of two community organizations that provide services to elders, and 14 community members. The meeting was facilitated by one of the management level staff at HHI. Food and drinks were provided. In general, the people present at this meeting were open and willing to share their opinions.

4.1.1 Outreach

The first topic discussed during this meeting was how best to outreach to Wilkinsburg seniors. Community members reported that many Wilkinsburg area seniors travel to East Liberty to get senior programming at Vintage Senior Center. Vintage offers a large variety of programming as well as adult day care. Community members proposed that HHI perhaps try to offer a local alternative to Vintage. One of the main ideas regarding outreach efforts for any new programming to come out of this meeting was to emphasize what HHI already has in place and communicate the message that seniors are welcome there. One participant mentioned that HHI has the only heated swimming pool in all of Wilkinsburg, which was seen as an asset. In addition, some participants proposed sending out existing HBFP class coaches and participants to talk in the community with seniors regarding participating in exercise classes. Another participant added that these “ambassadors” of the class should be willing to talk with seniors and listen to their stories. This participant felt that seniors are often lonely and would enjoy having someone to talk with, and this in turn would make them feel welcome at HHI. Many existing HBFP class participants were present at this meeting, and several of them felt very positive about what the program has done for them. One participant reported being able to reduce the number of medications he was taking after becoming more active and losing weight. He felt this benefit should be emphasized to encourage elders to come to HHI and exercise. The majority of attendees recommended thinking through the issue of transportation in order to improve outreach and recruitment efficacy. They agreed that transportation could be problematic for many low income seniors residing in Wilkinsburg. Some alternatives were presented regarding this potential barrier: take

programming to senior centers and senior high-rises, assist seniors with registration for Access or OPT,¹¹ and consider ways to make seniors feel safe traveling back and forth. Some specific community-based locations such as senior high-rises, apartment complexes with a large senior population, and area churches were mentioned as possible sites to provide exercise and education classes and / or to advertise HHI's provision of programming for seniors. The meeting participants were valuable sources of knowledge regarding buildings that needed to be approached through tenant councils and who the contact people might be.

4.1.2 Programming

Specific issues regarding possible programming were discussed. Meeting participants suggested the following topics: nutrition; healthy shopping; how to de-stress; social and entertainment events; movies; music; dancing; photography; and bridge classes and other card games. Ideas for a kick-off event were discussed. The idea of a health fair was put forth, with the plan that health related vendors and organizations would have tables and provide door prizes. The best times for programs were also discussed. Meeting participants felt that morning activities might be best, as this is the time of day when elders are the most active. In addition, the schools in Wilkinsburg let out between 2:30 and 3:00 pm, and they are located next to HHI. Many students walk past HHI on their way out of school, and several meeting attendees felt this could be intimidating to seniors coming to HHI.

¹¹ Access and OPT are local public transportation for seniors and people with disabilities.

4.1.3 Research

At the meetings, interest in health research participation was also discussed. A general description of a proposed research project was given by the BCHS professor and the opinions solicited. The community members felt that the research project was reasonable to attempt and could be accomplished successfully. They were very excited at the idea of a grocery store gift certificate provided to research participants at the study visit. In fact, most community members were so excited about this that they spontaneously voiced their desire to participate in the study.

4.2 OCTOBER 24, 2006

The purpose of the second meeting was to plan for a Senior Health Fair to be held at HHI. The discussion centered on two topics: 1) ideas relating directly to the health fair or ongoing programming; and 2) ideas for communicating about the fair to the community to encourage attendance. One HHI staffer, myself, and five community members were in attendance at this meeting. The meeting was co-facilitated by the HHI staffer and me.

4.2.1 Senior health fair & ongoing programming

A variety of ideas was presented either for inclusion at the health fair or for ongoing programming for seniors at HHI. One participant suggested that lunch be provided, as it

is at most senior centers (including Vintage). Other participants wanted a short survey created with fields for the health fair attendee's name, contact information, and an inventory of preferences for ongoing programming. Demonstrations were mentioned as a good idea for the health fair. The existing HBFP exercise classes could put on small demonstrations and someone could do some healthy cooking demonstrations. Meeting attendees also wanted information provided at the fair regarding a May 2007 referendum regarding property taxes vs. earned income tax as the basis of school taxes and learning how to use new voting machines properly.¹² Additional programming ideas mentioned included: dancing, bingo, card games, and Tai Chi. Opinions regarding types of door prizes to be offered were also solicited. Ideas from the community members including grocery store gift certificates, throw blankets, winter clothing such as scarves, hats, and gloves, fruit baskets, bath products, and first aid supplies.

4.2.2 Communicating with the community

Community members' ideas regarding communication were explored through several questions. One question I asked them was, "What are the locations where people in Wilkinsburg get information regarding the community?" A variety of information sources were provided ranging from senior centers to social groups. See Table 3 for a complete list of locations.

I also wanted to know what media sources are important in the community in order to get ideas about communicating program offerings at HHI with Wilkinsburg.

¹² This meeting took place just before the November election in which many Allegheny County, Pennsylvania, polling places were slated to move to touch screen computerized voting machines.

Television was mentioned by a couple of participants. One person stated that one of the local cable channels scrolls a listing of upcoming local events, and another added that Comcast, Wilkinsburg's cable company, airs public service announcements for non-profit organizations. Several newspapers and circulars were mentioned. One participant stated that the Pittsburgh Post-Gazette's East section would be a good place to advertise programming for Wilkinsburg. Pittsburgh also has a weekly newspaper aimed at African American readers, the New Pittsburgh Courier. The Wilkinsburg community newsletter was once again mentioned, as was the Pennysaver, a weekly mailer with predominantly classified ads. Five different radio stations and several particular radio shows were mentioned by participants as being popular with older and / or African American listeners. Two of the stations were religious in nature, with one playing gospel music. Three of the stations play what one meeting participant described as "urban music." Additional publicity suggestions made by the meeting participants included hanging a banner over Penn Avenue,¹³ placing announcements in church bulletins, hanging posters, and distributing flyers.

Finally, I asked the meeting participants one of the most important questions regarding this type of communication—"What should the message be?" Some of the responses echo some of the comments made at the first community meeting regarding making elders feel welcome at HHI. The participants felt it was important to communicate that you can feel not only welcome, but also comfortable at HHI. Fellowship, friendship, and laughter were other messages that the meeting attendees felt strongly about because those feelings were based on their own experiences at HHI.

¹³ The main thoroughfare in Wilkinsburg Borough. Borough council would have to be consulted about hanging the banner.

Another general content area to be addressed in the message was what seniors would get out of coming to the health fair. The community members suggested emphasizing that correct information regarding health would be provided as would information regarding the rights and benefits that seniors have. Finally, all of the meeting participants felt that it was exceptionally important to emphasize that the fair would be “free, free, free.”

Table 3. Sources of community information reported by HHI meeting attendees

~Community newsletter
~Word of mouth
~Borough council meeting
~Banks
~Church
~Buses
~On cars (flyers)
~Penn Hills YMCA
~Shops on Penn Ave.
~Doctor’s office
~Senior centers
~Kingsley Association ¹⁴
~Neighborhood block clubs
~Wilksburg Red Hat Society ¹⁵

4.3 MARCH 1, 2007

During the third meeting, ongoing programming for seniors was discussed as well as health disparities experienced by African Americans aged 65 and older living in

¹⁴ A community center, much like HHI, located in the East Liberty area of Pittsburgh.

¹⁵ A social organization with many local chapters across the United States in which women aged 50 or over wear red hats and purple dresses and go out together purely to socialize and have fun.

Wilkinsburg Borough and / or Allegheny County, Pennsylvania. In attendance at this meeting were four community members and I who facilitated the meeting.

I explained that the purpose of this meeting was to identify specific health conditions of Wilkinsburg elders that we want to intervene on and for which we would like to develop programming. In light of that, I explained that I wanted to provide them with some data on which to base their decisions. I gave each participant a handout regarding demographic characteristics of Wilkinsburg residents and disparities in morbidity of African Americans as compared to whites (refer to Appendix C). I then discussed the handout as well as some additional data from the HBFPP regarding disparities in mortality. The meeting participants were very surprised by the disparities and stated that they had not heard anything about this before. One participant in particular stated that she was very angry about the numbers, and that this would propel her to give serious thought to what types of health programming should be provided to seniors in Wilkinsburg. Several of the attendees stated that this was very important information, and they wanted me to share this with the exercise class to which they belong.¹⁶

I asked them what they thought were important areas for health programming for seniors. Their answers were mental health, increased socialization, and nutrition. However, the overall feeling among the meeting participants was a desire to defer to a larger group. They felt they did not want to be making such a big decision for an entire group of people with input from only four people. We agreed that they would think about programming ideas for a future larger group meeting.

¹⁶ Which I did at a later date.

4.4 SUMMARY RESULTS ACROSS ALL MEETINGS

The barriers and facilitators discovered during the community meetings and during my practicum in general fall into different categories, demonstrating the complex interaction of factors at play in community-based outreach and recruitment efforts.

Community members discussed some of the barriers to participation for Wilkinsburg seniors. Their primary concern was transportation to and from HHI. Transportation can be influenced by several levels of factors. It may depend on individual level factors, such as whether people own a car and if they still drive. On an interpersonal level, knowing enough people to have access to a jitney¹⁷ driver can influence transportation. Frequently, the names and phone numbers of jitney drivers are spread through word of mouth. Transportation may be influenced by the community level factors of whether the elder can use Access or if the public buses come by their homes.

Community members discussed elders' need to feel safe going to and from HHI for exercise and health education classes. Again, this factor can influence transportation with an elder feeling safer with Access or a family member driving them to HHI than taking a bus. It would likely also influence the times of program offerings as elders may feel safer traveling during daytime hours. The meeting participants also stated another possible barrier that would influence the times selected for programming: seniors may be fearful if they had to come to HHI while the local schools were letting out.

¹⁷ An unlicensed taxi which is typically lower cost than a licensed taxi would be a frequent mode of transportation for the African American community in Wilkinsburg.

While these potential barriers were mentioned, more of the discussions focused on ways to facilitate participation in research and program offerings. From an individual level, several meeting attendees emphasized what they have personally gained from their participation in HHI programming such as reducing the number of medications taken. With regard to research, most individuals present at the first HHI meeting indicated that an incentive, such as a gift card, would encourage their participation. They also felt that providing lunch, free information, and potentially, services at a health fair would encourage elders to attend.

At an interpersonal level, the suggestion was made to have exercise class ambassadors go out into the community and talk with and listen to seniors. Having a warm interpersonal interaction was seen by the community members to be inviting. Instilling a welcoming and comfortable feeling in potential participants was mentioned by several people regarding what message should be communicated. They felt that the message should also be about having fun, making friends, and socializing. This directly echoes some of the findings in the focus group studies found during the literature review for this thesis.

At the organizational level, meeting participants advised that HHI should tout the assets that it already has in place and provide a variety of programming choices. Some of the program recommendations by the participants seem to indicate that even their definition of health is systemic in nature. These participants did not take a purely physical or medical perspective of health. They suggested social and entertainment programs as well as providing information regarding voting and taxes.

The discussion held at HHI regarding sources of information and communication modes continued the pattern of multiple levels of influence. Sources of information for the community included interpersonal channels such as word of mouth and conversations with doctors. Organizational level sources were mentioned as well such as advertising at senior centers, community centers, stores, and banks. Community level sources mentioned included the Wilkinsburg community newsletter, neighborhood block clubs, and flyers placed on cars. One government source of information was mentioned—borough council meetings. For the purposes of communicating program offerings to the Wilkinsburg community, many mass media channels were mentioned included television, newspapers, radio, and circulars. On a more organizational level, church bulletins were felt to be a good way to publicize HHI's programs.

There are two possible explanations for some of the comments to come out of the third community meeting in which health disparities and programming preferences were discussed. The possibility exists that this meeting illustrates two additional factors influencing the efficacy of outreach and recruitment programs. The participant who mentioned that she was very angry about the health disparities between whites and African Americans seemed motivated to act. Her anger was an energizing force, and perhaps this could be harnessed in such a way as to encourage her to participate in research and health programming and / or to encourage others to participate. Of paramount concern here would be carrying this out in an ethical way. I became quite concerned after the reaction of the meeting participants at this third meeting, and questioned whether I should have done more to prepare them for the potentially upsetting

nature of the information I was about to share¹⁸. The second factor illustrated in this meeting is a bit less clear to me. The group was not willing to make a final decision regarding program offerings. This could be explained in several ways. Perhaps they did not want others who are active within HBFP at HHI to think that only a few were making the decisions for everyone. Perhaps, they did not feel effective enough as a group to make the final decisions. Or perhaps, in addition to allowing other HBFP participants to have a say in the decision, they just wanted more time to weigh the various programming options. If their reticence to decide that night was due to lack of a feeling of group efficacy, this could affect outreach efforts. If the group does not have confidence in itself and the choices it makes, this will likely come across to potential participants and could act as a barrier.

¹⁸ I did alter the way I presented the information at a future date to the entire exercise class. I prepared them with some introductory statements that the information I was about to present them could be upsetting to some people. Once I shared the information, I stated that there could be something positive to do regarding the health disparities faced by the elderly in Wilkinsburg—help to intervene on those health conditions through health programming.

5.0 DISCUSSION

5.1 LIMITATIONS OF THIS STUDY AND OTHER PUBLISHED RESEARCH

While the nature of the collection of the qualitative data from the community meetings held during my practicum at HHI was not rigorous nor designed to be a research study, the data do provide a real world example of many of the issues presented in the literature regarding outreach and recruitment of minority elderly. Future studies could be designed to allow more concrete conclusions to be drawn. Opinions of community members could be collected through more formalized focus group methods and qualitative data coding via content analysis. Alternatively, a survey could be designed to assess preferences of community members regarding programming and outreach and recruitment strategies. Expanding the source of community members to the rest of Wilkinsburg (beyond the walls of HHI) would improve generalizability of study findings to the entire community. Most participants in the community meetings held during my practicum were already involved in programming at HHI. I would like to add to this conversation some of the limitations of the other published literature on recruitment which was presented earlier in this thesis.

Many of the studies reviewed present recruitment as though it were an afterthought. Of course it is not typically the primary purpose of the design of the study

being presented in the literature, but few studies seem to be designed with effective outreach and recruitment strategies to be tested. Typically the studies offer no comparison group. One method of recruitment is utilized for all study participants and then reported. Alternatively, multiple methods are used, but again, they are used for all potential participants and / or not systematically varied so the effects of different methods can be determined. When differing recruitment methods are tested head to head such as with Arian and colleagues (2003), the methods are being compared across two different studies. The applicability of any findings regarding recruitment efficacy from such a study can be questioned purely on the basis of the different study protocols, potentially different therapeutic agents used, differing risk / benefit ratios, and the like. Other potentially confounding variables were not controlled for. The ability to recruit participants with systematically varied methods and large enough numbers of participants to draw meaningful¹⁹ conclusions about effective approaches would go a long way to advancing the knowledge in this field.

The models of recruitment could use some further development and testing as well. Glanz, Rimer, and Lewis (2002) state that models are meant to pull from multiple theories and apply to specific situations. Future publications describing the models mentioned in this thesis under section 2.2 could be improved by explicitly stating their theoretical bases. The matching model seems as though it may draw from a systems theory as it specifies three levels of barriers and enablers that interact dynamically; however the authors do not specify if this is the case (Levkoff & Sanchez, 2003; McCallum & Arlien, 2006). Additional research on specific elements of the consumer-

¹⁹ Not just statistically significant results, but what health research typically calls clinically meaningful results.

centered models could provide insight into recruitment strategies. Areal, et al. (2003) mention four components to this model, so it would be nice to know if the individual components make a difference in recruitment efficacy. Alvarez and colleagues (2006) reported successfully recruiting 50 of 176 desired participants (at the time of publication) by using the community organization engagement model. They were working with a very difficult population, but I would be interested to know if the authors felt this model was successful for them in the end. At the time of publication, they had less than one third of their total desired N. In the professional and volunteer staffing model, it is unclear what the key components of the model are that lead to successful recruitment. Is it just the fact that there are volunteers? Is it the fact that some of them received free services at the clinic? Or does it have more to do with the culturally tailored nature of the several programs mentioned by Kiger (2003)? The PEN-3 model seems to be the most developed and researched model out of the five I presented. But Airhihenbuwa (1993) developed it as a public health planning model, and it does not specifically describe recruitment into health research. Finally, many of these models seem as though they are not mutually exclusive. Systems theory provides a framework to integrate many of them. What would happen if we did this? In fact integrating all five models sounds reasonable if a community advisory board advocated trying for outreach and recruitment. We could match the perspectives of the investigators and potential participants by evaluating barriers and enablers at three system levels. We could additionally utilize the consumer-centered approach of having an advisory board, disseminating research results, and so on. We could do all of this while engaging other community organizations to collaborate with us and even have a presence on our community advisory board and utilizing

volunteers in our recruitment efforts. Finally, we could accomplish this with the culturally competent considerations outlined by Airhihenbuwa.

Given the laws and ethical principles surrounding the inclusion of minorities in research, more investigation should be done regarding what approaches work best for outreach and recruitment. The legal basis for this intensive focus on recruitment began with the *Nuremberg Code*. This came out of the trials of Nazi doctors following World War II. The doctors performed research of questionable importance without informing and seeking consent from the research subjects who were mostly concentration camp prisoners. In the U.S., the *Public Health Service Act* set forth the common rule in the Code of Federal Regulations. This governs human subjects research protection. The connection between human subjects research protection and recruitment is more clearly made when the *Belmont Report* is considered. The *Belmont Report* puts forth several ethical principles for human subjects research. One of these is the principle of justice, which means that risks and benefits need to be distributed fairly amongst the population. When we as a collective body of researchers complete clinical trials and other interventional studies that do not include a representative minority sample, we are violating the principle of justice. Most recently, the *NIH Revitalization Act of 1993* specified that investigators seeking federal funding must include women and minorities in research. The specific policies relating to this law are spelled out more thoroughly in *NIH guidelines on the inclusion of women and minorities as subjects in clinical research* from the Federal Register (1994). Investigators' plan for the specific recruitment of women and minorities must be included in the funding proposal. Despite these regulatory efforts to improve the participation of minorities in health research, this

continues to be a problem. Of even greater concern, as mentioned in section 1 of this thesis, health disparities persist for many segments of the population including African Americans and the elderly.

5.2 RECOMMENDATIONS REGARDING THE USE OF SYSTEMS THEORY IN COMMUNITY-BASED OUTREACH AND RECRUITMENT

I propose that a system put into place to use community-based outreach strategies to recruit African American elders for health research and programming is a CAS. The interconnected research institution, community organizations, community members, media outlets, doctors' offices, shops, governmental and policy bodies, and the like are the agents in the system. These agents are inherently diverse. They vary in size, scope of work, purpose of work, ethnic and racial background, professional training, and so on. This diversity amongst interconnected agents makes the system complex. Finally, if an ongoing collaborative partnership is formed among agents, the system will learn based on how effective various methods and processes prove to be. The system will evolve, and this makes it adaptive.

Complexity science is not some panacea that can provide all of the answers to the recruitment problems of health research endeavors. Unfortunately, it is a rather young science. As Zimmerman and colleagues (1998) note, "There are few proven theories in the field. It has not yet stood the test of time" (p. 7). However, it does provide a framework which is worth utilizing and testing. I have some recommendations for researchers based on my application of the framework to community-based recruitment.

Many of these suggestions are based on the book *Edgework: Insights From Complexity Science for Health Care Leaders* by Zimmerman, et al. (1998). This book provides a perspective on how complexity science can apply to health organizations. It provides practical recommendations and examples of real world health organization leaders who have employed complexity science.

First, because the degree of certainty is not high in a CAS, and because CASs act based on locally defined rules, the focus when operating in a CAS becomes more about process and relationships and less about specifying how every action should take place. In many fields what works well for one organization or in one setting is thought to be a good solution for other organizations and in other settings. This will become viewed as a best practice, and other organizations will try to replicate the same program following the exact same specifications. When this is done within the zone of complexity, it is likely to fail. In the zone of complexity, context matters, and location matters because of locally defined rules. This means recruitment methods that specify very detailed steps to recruitment, for example, being sure research staff attempt calling a potential participant three times to schedule an appointment are likely to fail frequently outside of their initial context. Perhaps in Wilkinsburg, I need to try calling people four times before they schedule. Perhaps a lot of people in Wilkinsburg do not have telephones so I will not be successful using phone calls to recruit people. Perhaps research staff should not be the ones making the phone calls.

Let us imagine that we have formed a community advisory board. Recall that with a CAS, several simple rules can combine to create complex behavior. First, instead of prescribing and proscribing very detailed behavior, a CAS approach to community-

based recruitment would spell out the bare minimum system specifications and instead of focusing on predicting all necessary system behavior, relationships among members of the board should be fostered (Zimmerman, et al., 1998). Through these interrelationships creative ideas regarding outreach and recruitment can be generated.

Second, because these detailed system rules do not need to be developed, micromanagement is not an effective leadership strategy. The leadership approach commonly used in community-based research strategies and community development fits well with complexity science. In these situations the leader needs to take on the role of a facilitator. I recommend that potentially one of the investigators who is skilled in facilitating meetings run the community advisory board meetings in this manner. Alternatively, one investigator and one community organization member could co-facilitate. This worked well during the second HHI meeting that was held as I co-facilitated with an HHI staffer. Zimmerman and colleagues (1998) suggest that good leaders in CASs are open to creative ideas being experimented with. They allow a variety of options to be explored, but they also have the wherewithal to reflect on the outcomes and decide what is working and what the next steps are (Zimmerman, et al., 1998).

This brings me to my third recommendation. Experimentation with multiple approaches at the same time is valid in a CAS (Zimmerman, et al., 1998). If a certain recruitment outcome is needed and multiple possible approaches are brainstormed, they may be tried at the same time and then evaluated for success. Zimmerman and colleagues (1998) suggest that this will allow the proper direction for the system to emerge from the system.

Fourth, given that we are attempting to create a diverse system of agents, in all likelihood there will be disagreements. When disagreements or paradoxes become evident, Zimmerman and colleagues (1998) recommend against ignoring them or shying away from them. Disagreement and paradox can be excellent sources of creativity within the system. The authors even suggest that one solution to warring factions would be to put them together in a working group and encourage them to come to a solution together. The facilitator of the community board needs to be very adept in these circumstances. A basic feeling of safety for the board members needs to be created by the facilitator or the group members will feel too uncomfortable to come up with a solution. Sterman (2006) speaks to this as he states that managers must build up an open and trusting environment in which people can dissent, question themselves, and admit that their own perspectives may have been incorrect. However, enough discomfort must also be created in the system because this is when groups can come up with their most creative solutions (Zimmerman, et al., 1998).

6.0 CONCLUSIONS

The literature review completed for this thesis has detailed many multilevel barriers and facilitators of participation of African American elders in health research and programming on the following system levels: individual, interpersonal, organizational, community, and other system level factors. The community meetings in which I took part at HHI illustrated a few potential barriers, but focused mainly on a variety of facilitators of participation.

I also introduced key ideas from systems theories beyond the social ecological model with which many public health practitioners are familiar. Additional systems theories which have been prevalent in other disciplines are beginning to become influential in the field of public health with new curriculum recommendations regarding systems thinking being made for MPH students by the ASPH. Specifically I explored the systems theory of CAS and made mention of some aspects of system dynamics which has provided the useful tool of virtual simulation of complex real world public health problems.

I recommended that a systems framework such as CAS be used in community-based outreach and recruitment of African American elders for health research and programming. This has the benefit of involving many agents within the community and promoting creative solutions to the problems of recruitment of minorities and elders.

Health disparities clearly remain a major problem for minority elders. One way to ameliorate these disparities is to improve the participation of minority elders in health improvement program and health research. Participation rates among African Americans and the elderly remain problematic despite governmental policy attempts to mandate a solution to the problem. A new approach is needed, and systems theory may provide the solution. As public health practitioners we have an ethical obligation to eliminate health disparities, and thus we have an ethical obligation to promote participation among underrepresented and underserved populations. Encouraging participation in research will allow findings to be more applicable to minority elders thereby enhancing intervention effectiveness, and increasing participation in health improvement programming and clinical services will improve minority elders' health status.

APPENDIX A: INSTITUTIONAL REVIEW BOARD EXEMPT STATUS

APPROVAL LETTER



University of Pittsburgh
Institutional Review Board

3500 Fifth Avenue
Ground Level
Pittsburgh, PA 15213
(412) 383-1480
(412) 383-1508 (fax)
<http://www.irb.pitt.edu>

Memorandum

TO: [C. ELIZABETH SARLES](#)

FROM: [SUE BEERS](#) PHD, Vice Chair

DATE: 5/29/2007

IRB#: PRO07050038

SUBJECT: Community dwelling minority elders' opinions of health research,
programming, communication, and outreach

The above-referenced project has been reviewed by the Institutional Review Board. Based on the information provided, this project meets all the necessary criteria for an exemption, and is

hereby designated as "exempt" under section 45 CFR 46.101(b)(4).

Please note the following information:

- If any modifications are made to this project, please contact the IRB Office to ensure it continues to meet the exempt category.
- Upon completion of your project, be sure to finalize the project by submitting a termination request.

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

APPENDIX B: HOSANNA HOUSE APPROVAL LETTER



Hosanna House Inc. ♦ Wilkesburg Community Center of Western Pennsylvania

May 24, 2007

To Whom It May Concern,

Both Sarles completed her Master's practicum here at Hosanna House, Inc., from August 2006 through May 2007. During this time, she participated in community meetings regarding the provision of senior programming and participants' opinions of research, recruitment, health communication, and the like. She maintained minutes from these meetings. I authorize her to use these meeting minutes, with identifying information removed, for the purposes of research for her Master's thesis.

If you would like to contact me, please call 412.342.1352 or email emilyg@hosannahouse.org.

Best regards,

Emily Galbreth
Development Associate

807 Wallace Avenue ♦ Wilkesburg, PA 15221 ♦ TEL. (412) 243-7711 ♦ FAX (412) 243-7733

"A place called home!" ♦ "One family, one future... committed to generations ahead!"

**APPENDIX C: DEMOGRAPHIC AND HEALTH INFORMATION FOR
WILKINSBURG BOROUGH, CITY OF PITTSBURGH, AND ALLEGHENY
COUNTY**

Census 2000 data

Wilkinsburg Borough total population: 19,196

Male: 44% (8439)

Female: 56% (10757)

65 yrs old and over: 15.8% (3039)

One race white: 29.3% (5615)

One race black or African American: 66.5% (12768)

Households with individuals 65 and older: 24.4% (2228)

Per capita income for the borough: \$16,890

Families below poverty level: 15.9%

Individuals below poverty level: 18.7%

Individuals 65 yrs and over below poverty level: 14.2% (national 9.9%)

Black or African American alone or in combination:

Aged 65 and older: 1507

Percent of Pop aged 65+ with a disability:48.2 (1383)

University Center for Social and Urban Research (UCSUR) (Figures taken from the Census)

City of Pgh 2000—Proportion of blacks age 65 and older: 12.4% (8.7% national)
85 and older—1.5% (0.9% national)

City of Pgh older people more likely to live in non-family households
-Low marital status
-High widow rate

Allegheny County: poverty rates among the elderly increase with age

Older black people poverty rate is at least 2.5 times that of whites in Allegheny County, PA, and US
It is 2 time that of whites in City of Pittsburgh

Source: Musa, Seiler, Flora, Briem, Martire, & Schulz, 2003

UCSUR Health Survey of Allegheny County residents 65+

	Hypertension	Stroke	Heart Disease	Diabetes	Arthritis	Any Current Cancer	Kidney Problem	Serious Respiratory Problem	Vision or hearing problem	Needs equip. due to health
White	48.3	9.6	32.0	16.6	55.2	4.5	6.6	13.8	40.6	17.7
Black	66.8	11.2	30.2	27.7	60.7	5.6	7.3	16.3	39.7	27.9

	Has add'l insurance on top of Medicare	Has prescription drug coverage	Takes prescription medications	Flu shot in the last year	Mammogram in last year (women)	PSA test in last year (men)	Current smoker	Current Drinker
White	89.6	73.6	85.8	71.1	50.5	69.4	8.7	45.1
Black	73.8	62.0	86.8	59.8	55.3	61.8	14.5	26.7

	Participates in physical activity	Watches diet / eats healthfully	Takes vitamins or supplements	Unable to do heavy housework	Receives help with personal care needs	Receives help with routine needs	Provides help with personal care needs	Provides help with routine needs
White	63.9	84.4	65.5	22.4	3.1	19.7	12.2	15.1
Black	52.8	85.9	52.2	31.8	5.0	25.0	10.0	14.3

	Heard of Area Agency on Aging (AAA)	Aware of AAA services	Have used senior services in last month	Not receiving needed senior services
White	69.2	28.1	12.3	6.0
Black	68.8	33.3	19.4	12.0

Source: Musa, Seiler, Flora, Briem, Martire, & Schulz, 2003

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