Challenges in Recruiting Aging Women Holocaust Survivors to a Case Control Study of Breast Cancer

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ABSTRACT

Older adults are underrepresented in medical research for many reasons, including recruitment difficulties. Recruitment of older adults for research studies is often a time-consuming process and can be more challenging when the study involves older adults with unique exposures to traumatic events and from minority groups. The current article provides a brief overview of (a) challenges encountered while recruiting aging women Holocaust survivors for a case control study and (b) strategies used for meeting those challenges. The case group comprised women Holocaust survivors who were recently diagnosed with breast cancer and the control group comprised healthy women from a Holocaust-survivor community in Israel.

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America's older adult population increased at a faster rate than the general population from 2000-2010; it is expected to double its current level of 42.3 million by 2050 (Howden & Meyer, 2011). Despite such rapid growth, older adults are underrepresented in medical research (Cruz-Jentoft, Carpena-Ruiz, Montero-Errasquín, Sánchez-Castellano, & Sánchez-García, 2013; Fitzsimmons, Blayney, Mina-Corkill, & Scott, 2014; Townsley, Selby, & Siu, 2005). Recruitment of older adults for research studies is often a difficult and time-consuming process, and can be even more challenging when the study involves older adults with past exposures to trauma or illness, and women from ethnic minorities (Areán, Alvidrez, Nery, Estes, & Linkins, 2003; Smith et al., 2007; Wendler et al., 2006).

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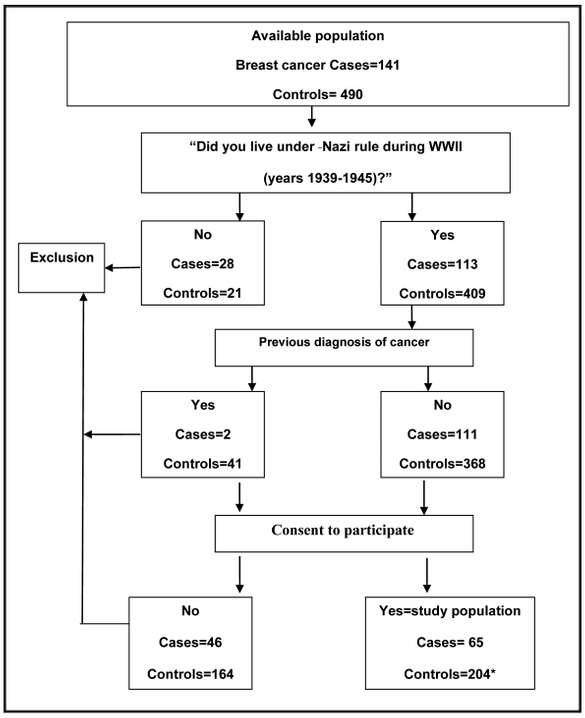

Figure. Study design.
* Four interviews were excluded due to inability of the interviewees to remember personal historical data.

Several participant factors have been associated with poor recruitment rates among older adults, including multiple chronic illnesses, lack of time, employment, caregiving commitments, travel to study sites, difficulties with the consent process, and understanding of study protocols (Cusack & O'Toole, 2013; Knechel, 2013; Mody et al., 2008). In addition, previous studies, such as the famous Tuskegee syphilis study, have shown that historical factors have led to mistrust in research and the medical system among older ethnic minority adults (Moreno-John et al., 2004).

Although cancer is a common health problem among older adults, members of ethnic minorities are also underrepresented in cancer research (McIlvane, Baker, Mingo, & Haley, 2008; Mishel et al., 2005), and only a few studies have examined recruitment strategies of older cancer patients (Puts et al., 2009). Puts et al. (2009) reported that the reasons for refusing to participate in medical studies among older, newly diagnosed cancer patients included anxiety, lack of interest, lack of time, and poor health.

Despite the growing attention targeted at older adults from ethnic minorities, there is inconsistent information on the effectiveness of recruitment strategies among them (Sood & Stahl, 2011; UyBico, Pavel, & Gross, 2007). To increase scientific knowledge and thus advance medical care and reduce health disparities, it is important that health researchers expand outreach efforts to include underrepresented older populations, including disadvantaged, minority, and nonminority older adults with chronic illnesses and disability (Sood & Stahl, 2011).

The current article provides a brief overview of (a) challenges encountered when trying to recruit aging women Holocaust survivors for a case control study and (b) strategies used for meeting these challenges. The case group comprised women Holocaust survivors who were recently diagnosed with breast cancer and the control group comprised healthy women from a Holocaust-survivor community in Israel.

BREAST CANCER CASE CONTROL STUDY AMONG ISRAELI JEWISH WORLD WAR II SURVIVORS

The authors conducted a breast cancer case control study among Israeli Jewish World War II (WWII) survivors from 2005-2010, which was designed to investigate the relationship between Holocaust-related posttraumatic stress disorder (PTSD) and hunger, and their shared impact on subsequent breast cancer risk (Vin-Raviv, Barchana, Linn, & Keinan-Boker, 2012; Vin-Raviv, Dekel, Barchana, Linn, & Keinan-Boker, 2014). In total, 65 breast cancer patients and 200 controls participated, with a 58.6% and 55.4% response rate, respectively. For eligibility, medical records were used to identify women Holocaust survivors with a histological confirmation of an in situ or invasive malignant breast tumor. These women were recruited through the oncology and radiology departments, as well as the outpatient oncology clinics, of five large Israeli medical centers. Controls were located through various voluntary assistance organizations for Holocaust survivors, such as the AMCHA Initiative, the Kibbutz Movement, local welfare departments, retirement homes, special facilities for WWII survivors, and the Foundation for the Benefit of Holocaust Victims in Israel.

Inclusion criteria included being a Jewish woman and current resident of Israel who was born in Europe prior to 1945 and who lived under Nazi rule during WWII (1939-1945) for at least 6 consecutive months. Exclusion criteria included a previous diagnosis of primary cancer (excluding squamous and basal cell carcinoma of skin), dementia or Alzheimer's disease, and immigration to Israel after 1989 (**Figure**).

A face-to-face interview lasting approximately 1.5 hours—using a detailed questionnaire that traced demographic details, health behavior, obstetrical and gy-

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necological factors, and war time experiences (including direct and proxy hunger exposure variables)—was conducted with each participant. In addition, a validated PTSD questionnaire, based on *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 1994) criteria and modified to capture WWII-related symptoms, was completed (Vin-Raviv et al., 2012, 2014).

Ethical Requirements

Holocaust survivors fall under the category of *vulnerable population* and may simultaneously experience factors that diminish their sense of autonomy (Copp, 1986), such as coping with psychological trauma of the Holocaust, the normal aging process, and being diagnosed with breast cancer. According to the U.S. Department of Health and Human Services' Institutional Review Board Guidebook (1993), several groups are considered vulnerable in research, including children, prisoners, mentally disabled individuals, economically or educationally disadvantaged individuals, traumatized and comatose patients, minorities, students, employees, and older adults. Therefore, each study protocol was carefully assessed and ethical considerations of study requirements were examined. It took approximately 1 year to receive institutional review board approval from the five participating medical centers.

Initial Recruitment Strategies and the Recruitment Process

Due to their personal histories (e.g., being forced to participate in medical experiments conducted by Nazi physicians in concentration camps [Paratz & Katz, 2011]), many Holocaust survivors have an understandable mistrust and fear of medical and public research (Ehrlich, 2004). Mistrust may become an even more prominent issue as Holocaust survivors cope with physiological changes brought on by aging and chronic medical conditions; they may interpret their old age or weakness as a sign of inevitable hardship or death (Baycrest, 2003). It has also been reported that some older adults perceive research to be intrusive through probing interviews or collecting medical samples (Cusack & O'Toole, 2013; Knechel, 2013). Among Holocaust survivors, such research may trigger traumatic memories related to the Holocaust, causing them to avoid research that includes intrusive testing (Kellermann, 2001). Therefore, prior to initiating the study, the primary researcher (N.V.-R.) held several meetings and consultations with leading experts who work with Holocaust survivors. Based on their recommendations, several strategies were built into the study design (Areán et al., 2003; Moore & Miller, 1999).

For the case group, a gatekeeping approach was used: in each medical center, key individuals (e.g., oncology nurses) served as gatekeepers (Moore & Miller, 1999). *Gatekeeping* occurs when access to someone or something is allowed or denied by a third party (Holloway & Wheeler, 2002). To enhance recruitment, a one-page explanation stressing the importance of the study was provided. After identifying a woman Holocaust survivor based on medical records, oncology nurses approached potential participants with this handout and offered them the opportunity to have a phone conversation with the primary researcher. If interested, demographic data and contact information were transferred to the primary researcher who then contacted them by phone. During the course of the study, the primary researcher made regular site visits at each medical center, providing information and updates.

The working procedure was more complicated among the control group and included: (a) an e-mail request by the primary researcher for a meeting with the organization's head; and (b) a subsequent meeting with each organization's team of health care professionals, during which the primary researcher explained the study and procedures, provided an overview of the benefits and costs to the organization, and discussed which strategy would best facilitate recruitment. The majority of these organizations facilitated a passive collaboration approach of recruitment (i.e., through lectures or pamphlets and posters). The organizations asked the primary researcher to deliver a lecture about the study directly to the Holocaust survivors, thereby giving them the opportunity to make their own decision about contributing. A staff member was always present during the lectures to assist the primary researcher, who answered all questions and addressed any concerns of the groups. The women were then invited to contact the primary researcher directly or through the professional health team.

Although previous studies have shown that an introductory lecture within the community and assistance from community members were fruitful when recruiting a multicultural sample of older adults (Greaney, Lees, Nigg, Saunders, & Clark, 2006; MacEntee et al., 2002), in the current study, this consumer-centered model was found to be less effective. A possible explanation for this noneffectiveness is the well-known conflict between the investigator seeking to recruit participants to the study and the professional community gatekeepers who mediate access to potential participants (Russell, Maraj, Wilson, Shedd-Steele,

& Champion, 2008). Although the professional community gatekeepers of the Holocaust survivors understood the importance of the study, they felt conflicted about supporting and imposing any burden on participants. Therefore, the women in the control group were less motivated to participate (Russell et al., 2008).

During the first 2 years of the study, fewer referrals were received than expected, but the organizations' passivity was understandable. Only toward the end of the 1980s and beginning of the 1990s did Israeli society begin to change its attitude toward Holocaust survivors, from ambivalence and denial to a more positive and respectful attitude (Solomon, 1995). These changes led to the development of specific organizations aimed to serve the needs of Holocaust survivors (Brodsky, Sharon, King, Be'er, & Shnoor, 2010). Although ELAH and AMCHA are recognized as prestigious and well-funded organizations in the fields of support and study of Holocaust survivors, they are bombarded by research proposals; they must therefore serve as gatekeepers, often hesitating to assist researchers or betray the trust they have rightfully earned from survivors. These considerations were also evident in the research encounter. Nevertheless, this over-restriction may have prevented some participants from contributing and may have caused a sample bias (Ewing et al., 2004). The researchers eventually made the decision to stop working with the organizations' gatekeeper approach and switch to direct recruitment. The primary researcher contacted the Foundation for the Benefit of Holocaust Victims in Israel and, after signing an agreement with them to protect participants' confidentiality, the foundation provided a confidential list of Holocaust survivors who met the study criteria. The primary researcher contacted the potential participants through phone calls.

A particular challenge was recruiting individuals who lived in three special facilities for Holocaust survivors under the State's supervision (Siegel-Itzkovich, 1999). These facilities function as nursing homes for individuals with cognitive and functional limitations who cannot live in the community. Individuals living in these facilities are protected by federal regulations and "institutionalized mentally infirm" (National Commission for the Protection of Human Subjects and Behavioral Research, 1978, p. xvii). This population presented numerous challenges for recruitment due to their comorbidities and the long ethical and research approval process necessitated by their vulnerable population status (McMurdo et al., 2011; Moore & Miller, 1999). The primary researcher worked with two of the three facilities for Holocaust survivors in attempting to recruit participants for the control group. Facility managers identified residents with no cognitive deficit who they believed were eligible for the study. The primary researcher was able to recruit six participants (who would ordinarily be unrepresented in this kind of study) to the control group.

Mistrust in Research

The greatest challenge was building relationships, gaining trust, and fully interacting with participants. Several strategies were successfully implemented during the recruitment process and throughout the interview phase. First, when the primary researcher contacted the participants by phone, she emphasized that there would be no medical examinations. Second, the researcher approached participants in a pleasant, courteous, respectful way, using nonthreatening verbal and body language. This manner of interacting is especially important when working with older adults and members of ethnic minorities (Farmer, Jackson, Camacho, & Hall, 2007). Third, being aware of the fact that providing testimony and retrieving memories from the past could induce stress among Holocaust survivors (Aviezer-Steiner, 2002), the researcher made the participants feel safe and comfortable, including interviewing them in their preferred environment and working at their pace. A few days after the interview, the researcher contacted participants to see how they were feeling and whether there was anything they needed, bringing a sense of closure to the experience. Finally, the researcher's status as a third generation Holocaust survivor helped create confidence and trust among participants. Making use of her background and extensive knowledge of WWII and the Holocaust, the researcher was able to prepare thoroughly for the interviews. The primary researcher had a working knowledge of Yiddish, Russian, and Lithuanian, and if participants found it difficult to express themselves in Hebrew (i.e., the language they acquired upon immigrating to Israel from Europe), they were encouraged to speak in a language with which they felt more comfortable. These methods were previously reported to have been used with ethnic minorities (Farmer et al., 2007; Linden et al., 2007; Smith et al., 2007) and the ability to implement them in the current study helped create trust, confidence, and a relaxed environment.

Coping With New Stressors

Puts et al. (2009) reported that "feeling too anxious in relation to a cancer diagnosis or treatment" (p. 5) was one of the leading reasons behind the refusal of older, newly di-

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agnosed cancer patients to participate in studies. In a pilot study, the authors found that the main reasons for refusal to participate among breast cancer patients was the difficulty in coping with new trauma (Hantman & Solomon, 2007; Peretz, Baider, Ever-Hadani, & De-Nour, 1994) and painful memories from the past (Vin-Raviv, Dekel, Barchana, Linn, & Keinan-Boker, 2011). Therefore, the recruitment strategy was changed from incident to prevalent cases diagnosed between 2005 and 2010. The mean time between diagnosis of breast cancer and the interview was 2.36 years (*SD* = 1.42 years), and the majority of participants had already finished active cancer treatment. Given the particular vulnerability of this group, each participant was reached by the oncology nurse prior to any attempt by the researcher to make contact to avoid potential distress.

Interview Timing

Finding a mutually agreeable time to conduct interviews was difficult. The researcher made sure during the first telephone call to take all participants' needs into account, asking where they would like the data collection to take place (e.g., home or elsewhere) and whether they would rather be interviewed alone or in the presence of a significant other (Moore & Miller, 1999). Some participants did not want to speak in front of family members and did not permit the researcher to come to their homes. In these cases, the researcher met them in a neutral place (e.g., coffee shop, mall). Likewise, the time of the interview was scheduled according to the participant's routine and lifestyle (Areán & Gallagher-Thompson, 1996).

DISCUSSION

Older adults are underrepresented in medical research for many reasons, including recruitment difficulties. Failure to recruit and enroll older populations (including disadvantaged, minority, and nonminority older adults with chronic illnesses and disabilities) in medical studies hampers the ability to gain a comprehensive understanding of differences among population subgroups and develop effective services and interventions (Yancey, Ortega, & Kumanyika, 2006). Ultimately, this failure jeopardizes social justice and equity in health care (Hussain-Gambles, Atkin, & Leese, 2004; Mosenifar, 2007). Notwithstanding widespread recognition of the need to include older diverse groups in health research, diverse samples are difficult to obtain, as many of the challenges that contribute to health disparities among older adults and members of ethnic minority groups also arise during the recruitment process.

Conducting a research study with older adults from ethnic minorities presents important issues and challenges. Among the Holocaust survivor population, these challenges include coping with the normal aging process (Shrira, Palgi, Ben-Ezra, & Shmotkin, 2010), new traumas (Hantman & Solomon, 2007; Peretz et al., 1994), and mistrust of research (Ehrlich, 2004). Nevertheless, it is evident that recruitment of such groups is possible as long as researchers are prepared to invest a significant amount of time, effort, and resources, and be flexible and adaptable in their approach. Strategic planning in recruitment specifically tailored to members of older adult and minority communities has been suggested (Areán et al., 2003; McSweeney, Pettey, Fischer, & Spellman, 2009; Sood & Stahl, 2011; UyBico et al., 2007), and includes (a) collaborating with community partners and community boards to develop recruitment materials; (b) conducting outreach; (c) building trust and rapport; (d) incorporating flexibility into schedules; and (e) working with individuals trusted by residents (i.e., gatekeepers).

The success of particular recruitment methods may vary in accordance with the characteristics of the targeted communities and nature of the research topic, meaning researchers cannot rely on community gatekeeper endorsement to recruit participants (Knobf et al., 2007). A multidimensional approach should be used, including mass mailings, personalized letters (targeted to the specific ethnic group), face-to-face recruitment, referrals (i.e., snowball sampling), culturally tailored flyers and invitations, directly contacting potential participants, using cultural insiders and/or unaffiliated intermediaries as recruiters, and advertising the research study in places likely to be accessed by ethnically diverse populations (Knobf et al., 2007; Ogilvie, Burgess-Pinto, & Caufield, 2008).

Mistrust of research has been identified as one of the central barriers to successful recruitment of ethnic minority groups, particularly among those who have historically been subjected to oppression, discrimination, or exploitation (Ding, Powe, Manson, Sherber, & Braunstein, 2007; Smith et al., 2007). In an attempt to build trust and diffuse tension between ethnic minority groups and health care systems, as well as academic researchers, it is essential that the targeted population be involved with the research team (Knobf et al., 2007). Strategies for developing trust among diverse racial/ethnic groups in research have been proposed, including forming genuine partnerships, fostering open communication (including community representatives on the research team), and involving

community members in developing research agendas and refining research protocols (Areán et al., 2003; Knobf et al., 2007; Russell et al., 2008). Research that lays a foundation of trust and establishes mutual respect among researchers, community members, and participants, and extends beyond the enrollment and data collection phases, is essential to enhance participation of diverse populations.

In addition, it is essential to foster trust by making the research process as transparent as possible. Difficulties with the consent process and understanding study protocols may add to this mistrust (Dunlop, Graham, Leroy, Glanz, & Dunlop, 2007), and are particularly problematic for older adults (Cusack & O'Toole, 2013; Harris & Dyson, 2001; Mody et al., 2008). Researchers should foster trust by acknowledging historical cases of discriminatory research protocols and verbally explaining the study to participants in nontechnical terms. For example, older adults (particularly those in residential care) demonstrate concern about loss of privacy (Applegate & Morse, 1994; Hall, Longhurst, & Higginson, 2009). Therefore, it must be explained that the study has safeguards, including strict confidentiality of interviews and personal health data. Participants should understand that they may have someone accompany them during interviews. The interviewer must be skilled in creating confidence and providing a relaxed environment, during which participants can feel assured they are being granted an opportunity to be heard. Older adults often do not believe they are being heard and, as a result, lose confidence in voicing their opinions when additional individuals are present during interviews. Research teams should be encouraged to address any concerns or reservations the potential participants have about research procedures.

Vulnerable populations (e.g., aging women Holocaust survivors) may be subject to specific ethical limitations, such as restricted procedures and sampling. Ethics committees closely examine the necessity and potential harm and benefit of questionnaires, laboratory assessments, and/or blood draws from older adults participating in research (Moore & Miller, 1999). Curtailing the length of questionnaires and interviews, limiting the total volume of biological samples taken to avoid potential distress, and minimizing all discomfort and injury should be considered when generating research protocol. Researchers should consider the use of appropriate alternative protocols in situations where sensitive and potentially distressing information will be gathered.

LIMITATIONS

The main limitations of the study relate to the recruitment process and that only one researcher conducted interviews. An interviewer cannot completely avoid bias (Davis, Couper, Janz, Caldwell, & Resnicow, 2010; Hennekens & Buring, 1987), and the way in which information is solicited, recorded, or interpreted is of relevance. In the current study, the primary researcher knew participants' disease status. Had more than one interviewer been used, interviewer bias could have been minimized or, if the interviewer were blinded to the outcome of the study, completely eliminated.

CONCLUSION

There is no "one size fits all" way to address recruitment of older adults from ethnic minorities for research studies. A thoughtful, detailed, and planned recruitment method tailored specifically to the targeted community must be developed. If researchers are willing to contend with and overcome study barriers, they will find that such studies are possible and of great value to the scientific literature.

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