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Cancer, employment, and American Indians: A participatory action research pilot study

S.R. Johnson¹, D. Finifrock², C.A. Marshall^{3,4}, J. Jaakola², J. Setterquist², H.L. Burross⁴, and F.S. Hodge⁵

¹Consultant, Duluth, MN, USA

²Fond du Lac Human Services, Cloquet, MN, USA

³Northern Arizona University, Flagstaff, USA

⁴University of Arizona, Tucson, USA

⁵University of California, Los Angeles, USA

Abstract

American Indian cancer survivors are an underserved and understudied group. In this pilot study we attempted to address, through participatory action research, missing information about those factors that serve to either facilitate employment or hinder it for adult cancer survivors. One task of the study was to develop and/or modify instrumentation that could be used in a subsequent, in-depth census study. The pilot sample consisted of 10 cancer survivors, all members of a Northern Minnesota American Indian tribe, and 10 family members. All survivors reported having health problems such as fatigue since their cancer treatments. Rehabilitation counselors can assist survivors and their family members by advising them in regard to employment discrimination and accommodations such as flexible work schedules.

Keywords

chronic illness; multicultural issues; psychosocial aspects of stress and coping

The purpose of this research was to identify those factors that serve to either facilitate employment or hinder it for adult Chippewa cancer survivors and their family members. The health-related significance and personal value (e.g., economic, self-esteem) of maintaining work roles during cancer treatment and following cancer treatment are important to understand. This may be particularly true for American Indians given the economic situation of many reservation-based American Indians (Gitter & Reagan, 2001). Little is known, however, about the employment experiences of American Indian cancer survivors. The study provides an example of participatory action research procedures (PAR) used in carrying out research with one American Indian tribe, a sovereign nation, and two academic institutions.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interests with respect to the authorship and/or publication of this article.

Descriptive data were collected from this population that is both understudied by rehabilitation researchers and underserved by rehabilitation counselors, from the perspective of both being American Indian (Marshall, 2001; Marshall, Day-Davila, & Mackin, 1992; Marshall, Johnson, & Lonetree, 1993; Marshall, Johnson, Wiggins, & Gotto, 1998; Marshall & Largo, 1999) and being either survivors or cosurvivors of cancer (Marshall, 2008). As the study was exploratory and descriptive by design, we examined the following:

- the extent to which any loss of function resulting from cancer or the residuals of cancer was reported to be permanently debilitating
- which supports (formal or natural) alleviate the long-term effects of any barriers to well-being
- which supports foster quality of life (QOL), including employment/productivity; how family members as well as the cancer survivor are coping with cancer and its treatment or residual effects; and how these factors, including caregiving activities, affect ability to work.

Method and Results

Participatory Research Process

As defined by Graves (1992), “the participatory research model is a vehicle for forming [a] partnership” (p. 222). Participatory research requires scientists and research stakeholders to partner in all phases of the research process from planning and agreeing on the research design to dissemination of results (Cochran et al., 2008). However, as noted by White, Suchowierska, and Campbell (2004), the lack of defined procedures for PAR restricts both training and replication. These authors called for scientists to document their PAR procedures, thereby making their research available to testing for generality and replicability. The knowledge gained from the procedures reported here can serve as a guide for rehabilitation researchers and practitioners seeking to conduct research with other tribal communities. In this section, we outline the steps taken in our work to engage the community, describe how consensus was reached using the mechanism of a research advisory committee, and describe how change was approached as a result of the pilot research.

Engaging the community and developing partnerships.—Successfully involving an American Indian community in the research process requires common cause. This work began by building on previously existing relationships. A key long-standing working relationship existed between an academic researcher experienced in community-based participatory research and a rehabilitation counseling practitioner who was also a cancer survivor, a tribal member, and a recipient of a cancer research training fellowship offered through the Native Researchers Cancer Control Training Program, Oregon Health & Science University, and the University of Arizona. As cancer had not been addressed in earlier community needs assessments conducted by the human resources division of the tribe, its administration was interested in our proposed research and wrote a letter of support that was included in the proposal for our pilot research. Engaging the community based on mutual interests resulted in a partnership the tasks of which included the joint formulation of

research questions, development of the research design, data collection, data analysis and interpretation, and dissemination of the results.

Facilitating congruence and consensus.—Engaging the community and building on established partnerships early in our process led to a commitment to the research from key community stakeholders. However, to develop congruence and to reach consensus among community stakeholders on how to proceed once our proposal was funded, we formed the Fond du Lac Cancer Research Advisory Committee (RAC). Indeed, such a community-based advisory committee is a key component of the participatory research process (e.g., Dunn & Chadwick, 2002). The RAC consisted of four interested community stakeholders from the health, rehabilitation, and human services areas of the Fond du Lac reservation. It is understood that a key aspect of partnerships in participatory research includes access to the project's budget (Cochran et al., 2008). In this study, a community member was hired to coordinate the study's research activities on the reservation. The local coordinator, who participated in the RAC, was both a member of the Chippewa tribe and a veteran of the public vocational rehabilitation program, having served more than 30 years as a rehabilitation counselor. The RAC assisted with the final selection of research instrumentation and with recruitment publicity, was consulted in the data analysis, and participated in the dissemination of results. Recruitment publicity was posted in tribal health centers as well as distributed through tribal newsletters and notices. Interested participants were screened by the local research coordinator who also participated in data collection. It must be acknowledged that an essential element of conducting research on a reservation is approval of the tribal government. The work of the RAC in reaching congruence and consensus concerning our research activities no doubt facilitated the approval of the government via resolution for our research to proceed.

Promoting change.—A key element in PAR is action following research. In this pilot study, community energy and support for the work were motivated by an interest to understand the needs of cancer survivors. Our work in providing support for the foundation of this understanding is acknowledged in the *Fond du Lac Band of Lake Superior Chippewa Wiidookaage Cancer Plan, 2007–2012* (http://cancercontrolplanet.cancer.gov/state_plans/Fond_du_Lac_Cancer_Control_Plan.pdf). Community partners are taking the lead role in deciding specific reservation-based action steps to follow this pilot effort. It was noted that further research would be welcomed, as trust in our process had been established, but also that further research might best wait until the tribe implemented its cancer plan.

Participants

A total of 20 adults was interviewed for this study. The majority of all research participants (80%) were female. Of those interviewed, 10 were cancer survivors and members of a Minnesota Chippewa tribe. The remaining 10 participants were adult family members identified by the cancer survivor research participants as someone having a substantial contribution or role in their lives and cancer experience. The majority of family members (60%) were also members of the Minnesota Chippewa tribe; the remaining 40% self-identified as non-Indian.

Procedure

Beginning with the initial tribal contact, researchers employed a PAR framework throughout all phases of the work. A \$50,000 special populations pilot research grant supported the work, to include the salary of a local, on-site research coordinator. Face-to-face interviews were conducted using a combination of structured and semistructured approaches (Patton, 2002). Apart from the demographic data collected, questionnaires focused on how the cancer experience affected individual employment or work experiences during cancer treatment and at the time of the study, both for the cancer survivor and for a supportive family member identified by the cancer survivor.

Data Collection

Data were collected from cancer patients/survivors via in-depth, personal interviews carried out by either the local research coordinator or the project director. Selected family members of these individuals (i.e., those family members identified by the participant as having made a substantial contribution or played an important role in his or her life and experience as a cancer survivor) also participated in separate interviews. The interviews were conducted in the home or selected environment of the research participants. Interviews were conducted face to face, using a semistructured format to ask questions prepared in advance. All instrumentation described below was administered via interview. A specific interview protocol was developed to ensure that interviewers followed the same order when administering the research instrumentation unless otherwise indicated by unanticipated events or circumstances of the interviews. Study participants received an honorarium of \$50, paid by check through the University of Arizona. After each interview, research participants were given contact information for vocational rehabilitation and other relevant human services.

Instrumentation

Using instruments that were culturally appropriate for the reservation setting was an important goal for the project. A demographic questionnaire and open-ended questions were developed by investigators following an intensive review of existing instrumentation and in partnership with the Fond du Lac Cancer RAC. None of the existing instruments employed had reliability or validity data based on Chippewa tribal populations, therefore, instruments were modified based on the professional and cultural experience of the RAC to fit the cultural and literacy needs of the tribal individuals.

Demographic information.—A 32-item questionnaire, *Cancer and Employment: Demographic Information*, was developed by the research team and used to obtain demographic data from the research participants. This questionnaire was derived, in part, from the Fond du Lac *Biennial Comprehensive Human Services Needs Assessment* survey instrument.

Quality of life instrumentation.—The *City of Hope's Quality of Life Patient/Cancer Survivor Version*, a 41-item ordinal scale, was used (<http://prc.coh.org/QOL-CS.pdf>) to measure physical, psychological, social, and spiritual well-being, with scoring based on a scale of 0 = *worst outcome* to 10 = *best outcome*. The authors reported overall test-retest

reliability of $r = .89$ and overall internal consistency of $\alpha = .93$. For our research, the RAC recommended two cultural modifications on items related to spiritual well-being. They recommended that (a) Item 35 be modified to read, “How important to you is your *participation* in spiritual activities such as praying, going to church, ceremonies?” and (b) Item 36 be modified to read, “How important to you are spiritual activities?” Also used was the 37-item *City of Hope’s Quality of Life Family Version* (<http://prc.coh.org/pdf/Quality%20of%20Life%20Family%20Version.pdf>) for which the authors reported similar psychometric properties: test-retest reliability of $r = .89$ and overall internal consistency of $\alpha = .69$.

The short version of *Your Health and Well-Being/SF-36v2* (<http://www.sf-36.org/tools/sfsurveys.aspx>), the SF-12v2, was used as a second QOL measure. The authors of the SF-12v2 have reported extensive psychometric data (Ware, Kosinski, Turner-Bowker, & Gandek, 2002). An example item from the SF-12v2 is, “During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?” Developers of this scale gave researchers approval to use the SF-12v2 as published, with the addition of four Item 11 statements from the SF-36v2, for instance, “I seem to get sick a little easier than other people”; this modification was at the request of the Fond du Lac RAC.

Work experiences/work limitations—Two instruments were used to measure work experiences and/or work limitations related to cancer:

1. **Work Experiences.** Helgeson and Tomich (2005) provided researchers with 11 items they developed to explore the work experiences of cancer survivors.
2. **Work Limitations Questionnaire (WLQ).** In terms of psychometric properties, the WLQ has been extensively validated and researched using both clinical and nonclinical populations (Lerner, Amick, Lee, et al., 2003; Lerner, Amick, Rogers, et al., 2001).

Open-ended questions—Eight open-ended questions related to both work experiences and QOL were developed by investigators in conjunction with the RAC. The experience and skills of the RAC, as described earlier, ensured that the questions were clear and had face validity for the tribal population. Final questions were accepted through the process of consensus versus using a statistical procedure such as interrater reliability:

1. What could your employer have done to make it easier for you to continue working after diagnosis?
2. How has cancer affected your plans for retirement?
3. How would you describe your family support during the cancer treatment?
4. Tell me about the services and supports you found most useful both during and after cancer treatment.
5. Tell me about the services and supports that you feel would have been helpful but that were not available to you, both during and after cancer treatment.

6. What barriers to employment or work did you encounter, if any?
7. Do you feel that the questionnaires we used and the questions we have asked were appropriate?
8. Is there anything you would like to add or to tell us?

Discussion

It is important to emphasize that as this work was a pilot study and exploratory, our results are descriptive in nature. In addition to our results, it is hoped that the procedures reported here can serve as a guide for rehabilitation researchers and practitioners seeking to conduct research with other tribal communities. Significant structural components of PAR that we used included engaging the community and developing partnerships, facilitating congruence and consensus in terms of the research design, and promoting change based on the results. With regard to the development of our partnership, in working with sovereign nations, it is important to understand that sharing power in research is most likely accomplished as a matter of course. For instance, it is understood when first engaging the community that unless tribal administration agrees to the research and supports the research through resolution, the research will not take place on tribal lands. Respect for the skills and abilities of partners allows for developing congruence and consensus with regard to the research approach. Finally, change based on the results of the research evolves as a direct result of both the findings and the community's readiness to act. Community support and ownership of the data is evidenced by coauthorship of publications and the approval of tribal administration to submit a manuscript for publication (Caldwell et al., 2005).

Overall, we were honored by the willingness of the research participants to contribute to this pilot effort. During the process of the study, researchers were welcomed into the homes of the study participants, offered nourishment, and given wild rice to take home. The procedures employed in this research provide an example of how two academic institutions and one tribal community successfully partnered in using PAR to carry out an initial study of cancer survivors in the community. The purpose of providing these results was to provide a framework for other rehabilitation researchers and practitioners in pursuing similar studies with underserved populations. We believe that this work can serve as an important guide for others as it is hoped that the results of this pilot research will provide evidence for, and interest in, further study.

Given that all survivors reported health problems, for instance, fatigue, since cancer treatment, it would be important to consider researching the effect on overall health of an intervention aimed at improving functioning for American Indian cancer survivors. In the field of rehabilitation, we have come to realize that not only should intervention be evidence based but all populations we serve must also be included in the evidence (Leung, Marshall, & Wilson, 2007). Better understanding the experiences of cancer survivors such as those presented here will allow, with subsequent research, the development and dissemination of evidence-based interventions. Half of the survivors in the pilot study had been diagnosed within 2 years of this research. Family members of these more recently diagnosed individuals reported having fears related to a second cancer, a recurrence, and metastasis;

they reported that the cancer had been distressing for the family, that health care had interfered with personal relationships, and that the illness had created a financial burden. This finding points to the need for clinicians and counselors to be particularly concerned with those individuals and their family members going through the immediate crisis of a cancer diagnosis.

A third of the survivors reported needing psychosocial supports while undergoing cancer treatment and needing accommodation from employers. In line with the findings of this study, reports from the Institute of Medicine have called for vocational rehabilitation services to assist cancer survivors (Hewitt, Greenfield, & Stovall, 2005) and have called for more psychosocial supports as well (Adler & Page, 2007). Whereas epidemiologists and rehabilitation researchers are most often concerned with large numbers of individuals, public health community-based nurses and rehabilitation counselors, for instance, can be concerned with the individual, oftentimes in statistical terms, with “the outlier,” “the exception,” the “stand-out.” It is important to remember that one of the American Indian survivors went from working part-time and being a student to being on disability and unable to work. We must therefore ask, “What information and rehabilitation services could have prevented this outcome?”

Flexible work schedules and supportive work environments appear to be important in the experiences of those participants who reported no problem with employment during their cancer experience. Innovative rehabilitation counselors can follow the lead of Parkinson (2009), who used her experience as a rehabilitation counselor to create a rehabilitation program within a cancer center.

Rehabilitation educators have encouraged the inclusion of family in rehabilitation practice (Ehrmann & Herbert, 2005). Rehabilitation counselors can include family members in their cancer-related outreach and interventions (Marshall, 2008). Although long-term disability and employment discrimination may not affect all cancer survivors (Stager, 2009), for those who are affected, rehabilitation can provide solutions through education, accommodation, and counseling with both survivors and their families.

Limitations

A limitation of the study was the small sample size ($N = 20$). However, this is the sample size that was proposed and is appropriate for a pilot study. In considering the results and drawing conclusions from this pilot study, it is important to remember that the results apply to the volunteers who participated in the study. As with any small descriptive study, we cannot draw conclusions concerning those who did not participate in the study. However, it is also true as noted by McDonald (2000) that a small sample in relation to a small tribe, as was the case in this pilot study, may actually represent a large representation of available participants.

Implications for Further Research

Initial data from pilot studies can assist researchers in estimating the effect size to be expected in subsequent similar and perhaps larger studies (Mertens, 1998). Effect size, calculated without regard to sample size and recommended for small studies, also allows

professionals such as public health nurses and counselors who prefer to commit errors of commission rather than omission to carry out their work of outreach and education with some degree of confidence in data that lend support to their clinical observations (Green & Glasgow, 2006). The pilot study reported here was carried out with one reservation, yet there are six Chippewa Indian Reservations in the state of Minnesota organized as the Minnesota Chippewa Tribe. There are 564 American Indian tribes and Alaska Native villages (U.S. Department of the Interior, 2010). There remains much work to be done with regard to documenting the needs and concerns of American Indian populations concerning employment issues and cancer.

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Biography

Sharon R. Johnson, MS, CRC, is retired from the State of Minnesota, Division of Rehabilitation Services, after more than 30 years as a rehabilitation counselor. Currently, she works as a consultant in participatory research and cancer from her home base in Duluth, Minnesota.

DeAnna Finifrock, RN, PHN, MSN, works for Public Health Nursing, Fond du Lac Human Services, in Cloquet, Minnesota.

Catherine A. Marshall, PhD, CRC, NCC, is a research professor in the Department of Educational Psychology, Northern Arizona University. She is the Frances McClelland Associate Research Professor; Frances McClelland Institute for Children, Youth, & Families; Norton School of Family & Consumer Sciences at the University of Arizona (UA). She is a senior scholar with the UA National Center of Excellence in Women's Health and an adjunct professor, Centre for National Research on Disability and Rehabilitation Medicine, Griffith University, Australia.

Julia (Bunny) Jaakola, MSW, is the behavioral health department coordinator at Fond du Lac Human Services in Cloquet, Minnesota.

Janette Setterquist, RN, is the evaluation and accreditation coordinator at Fond du Lac Human Services in Cloquet, Minnesota.

Heidi L. Burross, PhD, is a clinical assistant professor of educational psychology at the University of Arizona.

Felicia Schanche Hodge, DrPH, holds a joint position as a professor in the School of Nursing and a professor in the School of Public Health at the University of California, Los Angeles (UCLA). She is also the chair of the American Indian Studies program and the director of the Center for American Indian/Indigenous Research and Education (CAIIRE), UCLA.

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