

NATIONAL CANCER INSTITUTE SPECIAL PROJECT:

BARRIERS OF TRANSLATING ONCOLOGY RESEARCH
TO SOCIAL WORK PRACTICE

FINAL REPORT



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EXECUTIVE SUMMARY

In 2002, the National Cancer Institute (NCI) awarded the National Association of Social Workers (NASW) a grant to investigate how oncology social workers incorporate new research findings into their daily practice. The purpose of the project was to explore barriers to translating oncology research to social work practice, and to develop innovative dissemination strategies. The explosion of research and knowledge development in the fields of health and behavioral health has outpaced the social work profession's capacity to convert such findings into practical tools for use by practitioners. Through this project, NASW hoped to further the understanding of the dynamics of translating research to evidence-based social work practice, and to identify action strategies to bridge to gap between research and practice.

Barriers Identified

At the conclusion of the project, two major barriers to translating oncology research and social work practice had been identified. These included a lack of time and a lack of easy access to research findings.

Lack of Time

Participants noted that cutbacks in staffing and increased caseloads made it difficult to stay on top of new research findings. They explained that their institutions did not welcome research or see it as relevant to their clinical roles. As one social worker stated, "Social workers used to have to prove they were saving the hospital money. Now they need to show that they are making hospitals money." Views like these cut down tremendously on the ability to take advantage of educational opportunities.

Another participant noted that entire departments of social work have been eliminated, and still another person said, "Decentralization has really hurt social work."

It was agreed that it is a little easier to stay current if you work in specific area such as Bone Marrow Transplant (BMT) or a breast center. Even then, it is very difficult to stay current with related areas such as ethics, genetics, and end-of-life.

Lack of Easy Access

Participants discussed how difficult it was to find relevant research in an expeditious way. One stated that there is no systematic way to do it—there are no "oncology cliff notes." Few seemed to have a process for incorporating research into their practice.

Most of the participants desired ways that new information could be accessed easily and readily. For example, they mentioned having research findings presented at predominantly practice focused conferences. It would also be desirable for researchers to demonstrate how their research is applicable to the clinical setting.

Many participants noted that there is no centralized place to go to find psychosocial oncology research—that it takes effort to search for it. All agreed that concise, up-to-date information on the Internet would be very helpful.

Other barriers to staying current with research included:

- lack of mentoring
- lack of administrative support
- lack of funding for educational conferences
- decreased dialogue with other professionals
- misunderstanding about role of social work
- no positive reinforcement

Strategies for Improving the Linkage between Research and Practice

Participants expressed enthusiasm for a variety of strategies that would expand their knowledge of science-based interventions. The major areas noted that would strengthen the linkage between research and practice were: 1) more involvement of clinicians in the design and implementation of research projects; 2) expanded knowledge and use of Web resources by practitioners; and 3) coordination and consolidation of informational resources to allow quick access. NASW, as the major organization of social work practitioners, will continue efforts to expand its role in developing mechanisms to promote and support evidence-based practice. Primary initiatives will be to pursue collaboration opportunities with NCI, other potential funding partners, and with allied social work organizations. In addition, efforts are underway to develop and expand the research section of the NASW Web site as a primary avenue of diffusion and dissemination. NASW will also strengthen its role as an advocate in the area of health disparities, an issue with grave implications for populations that are frequently served by social workers.

NASW is grateful to the funding support of NCI and looks forward to continued partnerships to build the linkages between research and social work practice.

METHODOLOGY

(NASW) utilized qualitative research methodology to implement the grant. Two focus groups of oncology social workers were convened in areas with a high concentration of social workers. Twelve participants in Florida and 10 participants in California both met for two (2) hours to review the barriers to translating oncology research to social work practice. The benefits of using the focus groups for data collection were:

- **Experience of participants**

Oncology social workers at various stages of practice were extended an invitation to participate in the focus groups because the goal was to solicit data specific to social workers practicing in the oncology field. The participants were valuable in bringing their interest, experience, involvement, and knowledge of social work oncology.

- **Opportunity for brainstorming ideas**

Focus groups provide the opportunity to gather research with data beyond the structured questions. Brainstorming ideas for research dissemination allowed for the group to stimulate opinions that may not have been initially anticipated.

- **Efficiency of time and resources and cost effectiveness**

The cost and time saving measures allowed NASW to obtain a broad range of information. The Florida focus group was convened prior to a meeting of the Florida Society of Oncology Social Workers (FSOSW), and the California focus group was conducted at the USC/Norris Comprehensive Cancer Center and Hospital in Los Angeles with participants drawn from the Los Angeles area.

Focus group leaders were given a list of 15 questions (Appendix A) to trigger conversation among the group. They also administered a brief survey (Appendix B) to participants to collect demographic information and research and continuing education activities involvement data. These data were gathered, analyzed, and provided to expert panelists.

The expert panelists attended a Consensus Conference in Washington, DC, at the NASW National Office. Social workers serving on the expert panel were chosen for their 15 plus years experience in the field of oncology social work (Appendix C). They are researchers, publishers, and leaders in their specific

areas of expertise. Marcia DeSonier and Carol Marcusen, the focus group leaders, informed conference participants of the survey information collected from the focus groups.

The Consensus Conference also included a presentation by Dr. Joan Levy Zlotnik, titled “Social Work’s Contribution to Cancer Research: Summary of Draft Report to NCI,” and Dr. Jon Kerner, presented “Translating Research into Improved Outcomes.” Dr. Kerner highlighted the differences between research dissemination and research diffusion. The expert panelists, NCI staff and NASW staff attending were then able to analyze the implications of the data gathered, dialogue with one another, and recommend further action steps for research dissemination.

DISCUSSION OF FINDINGS

Demographics

All of the participants except one were women. They ranged in age from 27 to 67, with a mean of 45 years. Their experience in oncology social work ranged from nine months to 25 years. Twenty-three percent had less than five years of experience; 50 percent had between five and 15 years; and 27% had 16 or more years of experience. The mean number of years in oncology social work was 10.2 years.

The participants represented several practice settings, with the majority (68%) employed in cancer centers. Three were from community hospitals, two were from hospice, one was in private practice, and one was from a voluntary health association.

Almost 41% (n=14) of the participants belonged to both NASW and the Association of Oncology Social Work (AOSW). In total, 50% belonged to NASW (n=11) and 59% (n=13) belonged to AOSW. Other professional affiliations included the Clinical Social Work Society, the American Association of Nursing, the California Nursing Association, the Association of Death Education and Counseling, the National Hospice and Palliative Care Organization, the Society for Social Work Leadership in Health Care, the Florida Society of Oncology Social Workers, and the Association of Pediatric Oncology Social Workers.

Only two of the participants functioned outside of interdisciplinary teams. Over 4% (n=9) reported

very little or no supervision. Three of these were department directors and one was in private practice. The rest were primarily supervised by social workers, with one reporting supervision by a psychiatrist, one by a nurse, one by the non-social work manager of the cancer center, one by a product line manager, and two reported only peer supervision.

Specialty areas included general oncology (n=11), end-of-life/hospice (n=3), radiation oncology (n=3) adults only (n=2), pediatrics (n=1), and bone marrow transplant (n=2).

Salaries ranged from less than \$30,000 (n=1) to greater than \$75,000 (n=1). Nine individuals reported salaries between \$46-\$60,000 per year. The next most frequent level was \$30-\$45,000 with seven individuals falling in that category. Three of the participants did not yet hold social work licenses.

Research Participation

Only three participants indicated that they were currently engaged in oncology research. One was participating in an American Cancer Society study, one indicated she was a clinical site coordinator, and one had a Project on Death in America research grant.

Continuing Education

• Learning Style Preference

Choices for learning style preferences included written material, lecture, web, informal discussion, media (radio, TV), colleagues, supervision, and popular press.

Learning styles were ranked in order of preference as:

1. Lecture
2. Written materials
3. Informal discussion
4. Web
5. Clinical supervision
6. Colleagues
7. Media (radio,TV)

No one chose the popular press.

• Use of World Wide Web

When asked to rate the importance of the World Wide Web for staying current in the field, 50% rated the use of the Web as important, 36% said it was very important, and 13% said it was not very important or that they didn't use it.

Only six (27%) of the participants had ever taken a Web-based course. The course topics included substance abuse, AIDS, nursing, end-of-life, advocacy, and CPR. In contrast, almost 50% (n=10) of the participants stated they would be interested in Web-based learning.

Half of the respondents pay their own continuing education fees, and half of them have institutions that assist with the cost.

Use of Educational Materials

A variety of existing journals were used by the participants to try and remain current. Most frequently mentioned were the *Journal of Psychosocial Oncology*, *Cancer Practice*, *Social Work in Health Care*, *Oncology*, and the *Journal of Clinical Oncology*. One participant mentioned the *Oncology Nursing Forum* and one said she read the *New England Journal of Medicine*. However, several participants noted that the employer will no longer purchase social work journals. Another area of concern was that social workers often cannot find oncology research in social work journals, but most look outside the social work literature.

Several magazines and newsletters were mentioned. These included:

- *Social Work Today* magazine
- *Cure* magazine
- *Coping* magazine
- National Coalition for Cancer Survivorship (NCCS) *Networker*
- Association of Community Cancer Centers (ACCC) magazine
- Bone Marrow Transplant (BMT) newsletter

Other resources used to keep social workers current included patient education materials from NCI, the Leukemia and Lymphoma Society, and the Bone Marrow Transplant Society.

Additionally, several participants noted Web sites and Listservs they found useful. Both the Institute for the Advancement of Social Work Research (IASWR) and the Social Work Oncology Network (SWON) from AOSW, were mentioned as particularly helpful. Also www.cancerpage.com and Medline were cited.

One other item was mentioned. In major medical centers there are grand rounds, conferences, and tumor boards that can enhance social work education. However, social workers in these institutions do not always avail themselves of these opportunities.

One focus group had a discussion about the profession of social work itself being a barrier. Comments included statements such as: “We don’t challenge ourselves or our colleagues by asking for research to substantiate our theoretical concepts,” and “Social workers think research is optional—that it’s not necessary to the profession.” Other participants stated that new social work graduates do not come to the clinical setting with a research focus and that they do not recognize the importance of research to the field. One participant stated, “Social work is a passive profession, and we do not see ourselves as experts.” Another participant said, “As a profession, we are not in the forefront with owning competency. We know there are certain strategies and interventions that make a difference—look at end-of-life care—but we don’t claim that competency.” As a result, other professions do not ask for our opinions.

Importance of Social Work Research

Most participants agreed that evidence-based practice was essential for the survival of the profession, and that social workers need to back up their claims of effectiveness. A participant noted, “As a profession, social workers aren’t recognized for their scientific rigor. Our research is not always considered intellectually challenging.” Yet, others noted that social workers are excellent on the inquiry side — that they know what questions need to be asked and researched.

Several social workers who have made inroads in research were identified, particularly those researchers at hospice and at City of Hope. However, infrastructure challenges and a lack of fit of between clinicians and researchers also were mentioned.

Strategies for Improving Practice / Research Partnerships

Numerous areas for growth and for improving the practice / research partnership were identified:

- Mentors to help position the profession of social work in the interdisciplinary milieu. One participant described the task of becoming a researcher like “breaking into a whole new world which is technicolor, rather than black and white.”
- Co-sponsorship of research projects among interdisciplinary groups or among researchers and practitioners.
- Grants for staff positions to support research projects.
- Multisite research opportunities and projects by professional associations.

- Increased number of clinical trials with psychosocial focused research.
- Development of an updated oncology research bibliography that is placed on a permanent Web site.
- Development of a clearinghouse on psychosocial oncology research.
- Invitation to more researchers to speak at clinical practice conferences to bring new information in an easy-to-learn fashion.
- Better access to databases.
- Provision of training seminars for using the Web to access research.
- Development of a list of Web sites useful to oncology social workers.
- More on-line journals.
- Better applications of research findings to the field (clinical practice).
- Grants from professional associations for small research projects.
- Foundation grants to stimulate psychosocial oncology research.
- Writing assistance for practitioners who want to obtain research funding.
- Organization of journal clubs.
- Accessible continuing education offered by employers.
- Better education of other professionals about what social workers can contribute to the research process.
- Increased research articles in professional associations’ newsletters and Web sites.

RECOMMENDED ACTION STEPS FOR ADVANCING DISSEMINATION OF ONCOLOGY RESEARCH TO SOCIAL WORK PRACTICE

Collaboration

Expanded linkages and working relationships between NASW, the major organization of social work practitioners, and research institutions is a critical element if the Association is to assume a role in knowledge synthesis and dissemination of findings to guide service delivery. NASW will continue to pursue collaborative relationships and forums to bridge the gap between research and practice. Examples of current and potential collaborative links are:

- Pursue a continued collaborative opportunity with NCI to advance the translation of cancer research to oncology social work practice.

- Include more practitioners on editorial boards of NASW journals.
- Include more practitioners in guiding the development of NASW's Practice Research Network.
- Participate, support, and cooperate with programming of the Institute for the Advancement of Social Work Research (IASWR).
- Work with the Society for Social Work Research (SSWR) Conference, the Association of Oncology Social Work (AOSW) Conference, and the Biennial of the Intercultural Cancer Council (ICC) to hold a dialogue on the issues of "bench to trench."
- Work with relevant social work organizations on projects of relevance to oncology social work.
- Work with cancer advocacy groups (such as NCCS) on project of relevance to oncology social work.

Diffusion and Dissemination

NASW has several programs that contribute to the goals of advancing evidence-based practice. Through its publishing arm, the NASW Press, books, reference works and four peer review journals offer the most noted and frequently cited literature for the social work profession. These publications serve as a resource to educators, researchers, and practitioners. In addition, NASW develops and distributes numerous products that translate "best practices" and research findings into quick reference tools. These include a series of *Practice Updates* which are usually focused on practice settings or population specific topics, continuing education using both traditional seminar format as well as distance learning options, and electronic forums for information exchange. Examples of current and potential expansion of these activities include:

- Develop and disseminate Standards for social work practice with emphasis on emerging fields of knowledge. Examples are the recently adopted *NASW Standards for Cultural Competence in Social Work Practice*, and *NASW Standards for Integration of Genetics into Social Work Practice*.
- Develop a research and resource section on the NASW Web site that will highlight recent findings and include an interdisciplinary perspective. This will include posting or linking to the following:
 - *Everything You Wanted to Know About the NCI Grant Process*
 - *Translating Research into Improved Outcomes*
 - *Planning for Progress at the National Cancer Institute* Power Point presentation by Jon F. Kerner, PhD

- *Social Work's Contribution to Cancer Research: Summary of Final Report to NCI* Power Point presentation by Joan Levy Zlotnik, PhD, ACSW
- Increase the number of interdisciplinary journals included in *NASW's Social Work Abstracts*.
- Make available to NASW members highlights of successful academic / practitioner partnerships.
- Post final project report on the NASW Web site and on the Social Work Summit Listserv (n=48 member organizations).

Health Disparities

Social work has a well-established history and expertise in working with disadvantaged and high-risk populations. The profession works collectively on policy advocacy within service delivery systems and in public policy forums to raise awareness and seek reforms in the area of health disparities. There is extensive literature in social work about practice and interventions with high-risk populations, particularly among groups impacted by health disparities: racial minorities, both young and elderly persons, women, and low-income populations. NASW seeks to expand social work's contribution to addressing these important social problems. Current and planned initiatives include:

- Holding a meeting with the Office of Minority Health to discuss collaborative opportunities.
- Advocating for the formulation of a research agenda in the area of health disparities.
- Providing health disparities information to members via the NASW Web site and through publications, features in the *NASW News*, and in *Practice Updates*.
- Developing a formal policy statement on health disparities.
- Collaborating with the ICC on issues of mutual concern.
- Presenting a workshop on cultural competency in oncology care at the 9th Biennial of the Intercultural Cancer Council.
- Participating in continued involvement of the *Cancer Survival Toolbox*, a self-advocacy program initiated by the National Coalition for Cancer Survivorship.
- Using NASW's *Advocacy* Web page to highlight issues and request member articles regarding health disparities

Steps Requiring Additional Funding

Other areas of participation that NASW would like to develop are dependent on acquiring additional funding. These include:

- Establishing a practitioner oriented Web page regarding psychosocial oncology as it applies to the practice of social work.
- Developing a continuing education Web module for transferring oncology research to social work practice
- Developing a workshop curriculum for practitioners at relevant professional association meetings.
- Developing a consumer module for cancer advocacy based on psychosocial oncology research.

APPENDICES

Appendix A	Focus Group Discussion Guide
Appendix B	Focus Group Questionnaire
Appendix C	Biographical Sketches of Expert Panelists
Appendix D	<i>NASW News</i> articles <i>Grant Targets Oncology</i> and <i>Finding Psychosocial Oncology Research Should Be Easier for Social Workers</i>
Appendix E	<i>FSOSW Perspective</i> article <i>FSOSW Members Participate In Focus Group for NASW</i>

APPENDIX A

Focus Group Discussion Guide

1. Are you able to stay current with the research findings in your field?
2. How difficult is it to apply new research findings to your practice?
3. What barriers do you face in trying to stay current with oncology research?
4. Have these barriers changed in the last four or five years? If so, how?
5. What kinds of things would make it easier for you to stay current?
6. Which cancer-related journals do you read?
7. Which social work journals do you read?
8. Are there other written materials that you find useful for keeping current with oncology research?
9. What was a recent oncology research finding that you have applied in your practice? (Any psycho-social?)
10. How important is evidence-based practice in your day-to-day work?
11. How important is evidence-based practice for the social work profession?
12. How important are your interpersonal networks in helping you stay current?
13. What are strategies to improve the practice / research partnership?
14. What role can professional associations have in linking research and practice?
15. Other comments?

APPENDIX B

Focus Group Questionnaire

Barriers to Research Dissemination and Adoption of Evidence-Based Interventions

Individual Demographics

Gender: Female Male Age: _____

Degrees Held: _____

Do you hold a social work license? Yes No

Please indicate:

Number of years in social work practice _____

Number of years in oncology social work practice _____

Are you a member of NASW? Yes No

Are you a member of AOSW? Yes No

Are you a member of any other professional associations? Yes No

If so, please list.

In what type of setting do you practice?

Cancer Center Community Hospital

Physicians' Practice Private Practice

Agency Other (please specify) _____

Are you part of an interdisciplinary team? Yes No

What type of supervision do you receive and from whom (type of professional)?

Are you currently participating in oncology research? Yes No

If yes, what type? _____

If yes, what is your role in the research process? _____

Do you have a specialty area within oncology?

If so, please list. _____

What learning style do you find most useful?

- Written Material Lecture Web Informal Discussion
 Media (TV/Radio) Colleagues Clinical Supervision Popular Press

How important is the World Wide Web in helping you stay current in your field?

- Very Important Important Not Very Important

Have you ever taken a Web-based course? Yes No

If so, in what? _____

If not, is it something you might be interested in doing? Yes No

What barriers, if any, do you face with regards to web-based leaning?

- Discomfort with Web Learning Methods Lack of Relevant Web-based Courses
 Time Financial Resources None

What type of cancer-related educational conferences have you attended or plan to attend this year?

- International National Regional State Local Other _____

If there is a fee, who pays for your attendance? I do. My institution does.

Are CEUs important to you? Why or why not.

Please indicate your salary range? (optional)

- Less than \$30,000
 \$30-\$45,000
 \$46-\$60,000
 \$61-\$75,000
 Greater than \$75,000

APPENDIX C

NASW & NCI

Barriers of Translating Oncology Research to Social Work Practice

Expert Panelist List

Elizabeth J. Clark, PhD, ACSW, MPH
National Association of Social Workers

Becky S. Corbett, ACSW, LCSW, PIP
National Association of Social Workers

Ellen Csikai, PhD, MSW, MPH
Stephen F. Austin State University
School of Social Work

Marcia DeSonier, MSW, ACSW, LCSW, DCSW
Baptist Hospital
Cancer Support Services

Suzanne Heurtin-Roberts, PhD, MSW
National Cancer Institute

Marie Lauria, MSW, ACSW, LCSW, DCSW, BCD
Oncology Social Work Consultant

Carol Marcusen, MSW, LCSW, BCD
USC/Norris Comprehensive Care Center & Hospital

Shirley Otis-Green, MSW, ACSW, LCSW
City of Hope National Medicine Center
Supportive Care and Palliative Medicine

Cleora Roberts, PhD, ACSW
University of South Florida
School of Social Work

Susan Rubin, MA, MBA
National Association of Social Workers

Gina Tesauro, MSW
National Cancer Institute

Nicole Vennell, MSW
National Cancer Institute

Gail Woods Waller, MSM
National Association of Social Workers

Toby Weismiller, MSW, ACSW
National Association of Social Workers

Joan Oppenheimer Weiss, MSW, LICSW, LCSW
Consultant in Genetic Support

Tracy Whitaker, MSW, ACSW
National Association of Social Workers

Joan Levy Zlotnik, PhD, ACSW
Institute for the Advancement of Social Work
Research (IASWR)

BIOGRAPHICAL SKETCHES OF EXPERT PANELISTS

Elizabeth J. Clark, PhD, ACSW, MPH

Dr. Elizabeth Clark is the Executive Director of the National Association of Social Workers (NASW). Representing 150,000 social workers in 56 chapters and abroad, the mission of NASW is to promote the quality of social work practice and advocate for the improvement of social conditions.

Dr. Clark's clinical specialty area is oncology social work. She has conducted research and published papers and book chapters in numerous journals on psychosocial oncology and loss and bereavement. She is an editor of the book *Social Work and Oncology: Supporting Survivors, Families, and Caregivers*, published by the American Cancer Society, and she serves on the Editorial Board of *CURE: Cancer Updates, Research, and Education*, and the journal *Illness, Crisis, and Loss*.

Dr. Clark has been the author and project director for an educational grant, the *Cancer Survival Toolbox*®, a self-advocacy training program for persons with cancer. The *Toolbox*® received the Gold Star Award from the Cancer Patient Education Network of the National Cancer Institute in 2000. She received the Outstanding Service Award from the New Jersey State Commission on Cancer Research in 1994, and she chaired the American Cancer Society's Medical Affairs Advisory Group on Social Work Training from 1999-2001. Dr. Clark currently is the principal investigator for a Project on Death in America grant to establish standards for social workers in end-of-life care. In 2003, she became a partner in the National Dialogue on Cancer and serves on the workforce task force.

Dr. Clark is a past president of the National Coalition for Cancer Survivorship, and is a current board member of the Intercultural Cancer Council and the Institute for Advanced Social Work Research. She has received numerous honors including the Leadership in Oncology Social Work Award from the Association of Oncology Social Work, the Distinguished Public Service Award from Rockefeller College, State University of New York at Albany, and the DeWitt Clinton Masonic Award for Community Service for her work in cancer survivorship. Dr. Clark is also a member of the Academy of Certified Social Workers.

Becky S. Corbett, ACSW, LCSW, PIP

Becky S. Corbett is the Special Assistant to the Executive Director at NASW and has 12 years experience in non-profit management. Her background includes working with community mental health centers in the areas of mental health, mental retardation and substance abuse both as a practitioner and administrator. She has also owned a business where she provided consultation and training to healthcare organizations and she previously managed continuing education for NASW. Ms. Corbett received her MSW with a concentration in planning and management and her BS in human development and family studies from The University of Alabama (Tuscaloosa). She is a member of the Academy of Certified Social Workers (ACSW) from NASW, the American Society for Association Executives, and is licensed in the state of Alabama as a Licensed Certified Social Worker and Private Independent Practitioner.

Ellen L. Csikai, PhD, MSW, MPH

Dr. Ellen Csikai has been teaching in the School of Social Work at Stephen F. Austin State University for the past six years (degrees from the University of Pittsburgh). This past year she also has served as interim MSW program director. She teaches both practice and research courses. During that time she has pursued research in end of life care issues including current project funded by the Project on Death in America aimed at the construction of a data-driven end-of-life care continuing education curriculum for social workers. Other studies undertaken have included examining ethical issues that social workers face in end of life care including samples of hospital, hospice, and oncology social workers. She has used both quantitative and qualitative methods in her research. Dr. Csikai's practice background is in medical social work including trauma, intensive care, and emergency work in two hospitals in Pittsburgh, Pennsylvania, and in hospice care.

Beginning fall 2003, Dr. Csikai will be moving to teach in the School of Social Work of the University of Alabama (Tuscaloosa). She will teach practice, research, and in the health concentration. She is included as a consultant in a grant proposal to the Fetzer Institute regarding the role of religion, spirituality, and social support in the coping of palliative caregivers.

Marcia DeSonier, MSW, ACSW, LCSW, DCSW

Marcia DeSonier's education began in biology and nursing. After working as a nurse for several years, she found that psychosocial issues facing people with illness was much more interesting than their physical condition. She earned her Masters of Social Work at Florida State University in 1982. Since 1983, she has worked in the field of oncology at Baptist Hospital in Pensacola, Florida. Ms. DeSonier began her work as the oncology social worker on the oncology unit then as the Coordinator of Cancer Support. In this position, she provided patient education to individuals with cancer and their families as well as developed patient education materials. She began cancer support groups in the community as well as educational programs. In this position, Ms. DeSonier also continued many of the social work activities as well as performed cancer program responsibilities.

Ms. DeSonier has enjoyed being a volunteer in her professional organizations. In NASW, she has served as an officer at the unit, state, and national level. She has also served as an officer in the Florida Society of Oncology Social Workers. In the Association of Oncology Social Workers, she has been a regional director as well as conference chair for the Vancouver conference in 2000. For several years, Ms. DeSonier has been the state trainer for the American Cancer Society's *I Can Cope* program. In 1993, she was appointed by the Governor of Florida to the Florida Cancer Control and Research Advisory Council and will continue to serve until 2006. And, for fun, she serves on the Architectural Review Board for the historical city of Pensacola.

Ms. DeSonier's license is issued by Florida and is a Licensed Clinical Social Worker. She is a member of NASW's Academy of Certified Social Workers (ACSW) and Diplomate in Clinical Social Work (DCSW) and is listed in NASW's *Register of Clinical Social Workers*.

Suzanne Heurtin-Roberts, PhD, MSW

Dr. Suzanne Heurtin-Roberts is a social worker and medical anthropologist who also holds a degree in sociology. (PhD University of California, San Francisco, 1988; MSW, University of California, Berkeley, 1992; MA University of New Orleans, 1979). Dr. Heurtin-Roberts is Health Disparities Research Coordinator for the National Cancer Institute's (NCI) Behavioral Research Program, Program Director of the Centers for Population Health and Health Disparities, and former Chair of NCI's Health Disparities Research Coordinating Council. She founded and chairs the Office of Behavioral and Social Science Research's (OBSSR) Cultural and Qualitative Research Interest Group and led the task force that produced the 2001 OBSSR report "Qualitative Methods in Health Research" (NIH pub. No. 02-5046).

Dr. Heurtin-Roberts' research interests include the social determinants of health and health disparities, cultural representations of illness and behavior, adherence and qualitative methodologies. She has published in the areas of chronic illness, hypertension, qualitative methodology, African American and Russian health and mental health. Prior to coming to NCI, Dr. Heurtin-Roberts was Director of the Prevention Research Program for Special Populations at the NIAAA. Dr. Heurtin-Roberts was on the Social Work Faculty of the Catholic University of America from 1994-1999 where she taught graduate courses in the health care system, cultural diversity, and research methods and led a student cultural diversity group. Active in professional organizations in both anthropology and social work, Dr. Heurtin-Roberts is an elected member of the Executive Board of the Society for Medical Anthropology (1999-2002) and the American Anthropological Association's Committee on Public Policy. She also currently serves on the DHHS Subcommittee on Populations of the National Committee on Vital and Health Statistics.

Marie M. Lauria, MSW, ACSW, LCSW, DCSW, BCD

Marie Lauria is an oncology social work consultant in Chapel Hill, North Carolina, and holds an appointment as clinical associate professor in Pediatrics at the University of North Carolina in Chapel Hill. She practiced in pediatric oncology for 23 years at the University of North Carolina Hospitals. Ms. Lauria is a Board Certified Diplomate of the American Board of Examiners in Clinical Social Work (BCD). She is also a member of the Academy of Certified Social Workers (ACSW) and a Diplomate in Clinical Social Work (DCSW) of NASW.

Ms. Lauria is a past president and founding member both of the Association of Oncology Social Work (AOSW) and of the Association of Pediatric Oncology Social Workers (APOSW). She serves on the national and North Carolina Chapter Boards of Trustees of the Leukemia and Lymphoma Society. She chairs the American Cancer Society's (ACS) Children and Cancer Advisory Group and is the ACS representative to the Alliance for Childhood Cancer. She is also a member of the ACS Ends Committee on Quality of Life and the Patient Navigation Oversight Committee. Ms. Lauria is a member of the American Society of Clinical Oncology's (ASCO) Advisory Panel on Childhood Cancer. She is on the editorial board of the *Journal of Psychosocial Oncology*. Ms. Lauria is coeditor of the 2001 American Cancer Society book, *Social Work in Oncology: Supporting Survivors, Families, and Caregivers*. She is a Collaborating Partner in the National Dialogue on Cancer and is involved in the work of the Access to Quality Care issue team.

Carol P. Marcusen, MSW, LCSW, BCD

Carol Marcusen is the Director of Social Services, Case Management, Pastoral Care, and Patient Education at the USC/Norris Comprehensive Cancer Center and Hospital in Los Angeles. Ms. Marcusen brings 20 plus years of experience as a clinical social worker specializing in cancer. She is also a Field Instructor for the USC School of Social Work graduate program. She is widely published and has written many grants over the past 20 years.

Ms. Marcusen has a vast experience at program development and as a facilitator for numerous support groups for cancer patients. She continues to organize the monthly Prostate Forums being held at the USC/Norris Cancer Hospital. She also facilitates the "For Men Only" support groups at the hospital.

She is currently the Immediate Past President of the Association of Oncology Social Work (AOSW), an international organization dedicated to the enhancement of psychosocial services to people with cancer and their families. She has been active in AOSW on a national level since 1990, providing workshops and presentations at the national conferences, and as a Board member.

Ms. Marcusen was a core participant and author in the development of the *Cancer Survival Toolbox*® program for cancer patients. Her publications are many and include articles in cancer-related magazines such as *Coping*, *Quality of Life – A Nursing Challenge*, and a chapter in a book for physicians treating breast cancer, *Breast Care A Clinical Guidebook to the Evaluation and Management of Female Breast Problems*.

Shirley Otis-Green, MSW, ACSW, LCSW

Shirley Otis-Green is the Clinical Program Manager Psychoeducation Support for the Supportive Care and Palliative Medicine Department at the City of Hope National Medical Center in Duarte, California where she is responsible for program planning, development and management of various integrative psychosocial services. She created and coordinates the *Transitions Program*, which offers enhanced end of life psycho-educational services for the dying, the bereaved and those who care for them, where she is responsible for staff supervision, research, budgeting and fund-raising. Ms. Otis-Green is a co-founder of the San Gabriel Valley End of Life Community Coalition.

Additionally, she is the designated social worker for the Interdisciplinary Pain Management Team, the facilitator of several support groups, and a member of multiple medical center committees. She is the recipient of numerous professional and educational honors including the inaugural *Heart of Hope Award* at City of Hope and the Southern California Cancer Pain Initiative's *Award of Excellence*. Ms. Otis-Green recently received a *Social Work Leadership Development Award* from the Project on Death in America for her work on enhancing end of life and bereavement support services for Latinos. She is a research consultant for various quality of life grants in collaboration with the Department of Nursing Education and Research with whom she has co-authored numerous publications. Ms. Otis-Green is a community educator and has presented at professional conferences throughout the United States and Canada. She provides psychosocial assessments, crisis intervention, advocacy and support services to patients and their families as they cope with life-threatening situations. Her professional interests revolve around end of life care and integrated symptom management.

Ms. Otis-Green received her MSW from the University of Hawaii, and her BA from the University of Wisconsin-La Crosse. She is a member of the Association of Oncology Social Work and the NASW the Academy of Certified Social Workers, and is a Licensed Clinical Social Worker. Prior to coming to the City of Hope, she has worked in the areas of hospice, foster care, teen pregnancy and sexual abuse. Ms. Otis-Green has done private practice in adoption work and has taught a semester long course at the University of Hawaii School of Social Work.

Cleora Roberts, PhD, ACSW

Dr. Cleora Roberts received her MSW from Ohio State University in 1964. She practiced in mental health and child welfare settings before joining the Family Practice Center in Saginaw, Michigan, where she was the director of behavioral science training for family physicians. In 1982, Dr. Roberts enrolled in the doctoral program in the College of Education at Georgia State University and received her PhD in 1986 with research and statistics as her cognate area.

Dr. Roberts' dissertation topic was the research-practice gap in social work. One finding was identifying a need for practice-relevant clinical research in social work. In 1987, she joined the Psychosocial Oncology staff at the newly opened H. Lee Moffitt Cancer Center in Tampa. Dr. Roberts joined the faculty of the School of Social Work at the University of South Florida in 1987 and continued her research at Moffitt. She has published in *Health and Social Work*, *Social Work in Health Care*, and the *Journal of Psychosocial Oncology*.

Since 2001, Dr. Roberts has been on the Board of the Association of Oncology Social Work and served as the Chairperson of their Social Work Oncology Research Group (SWORG). They are currently publishing *A Social Work Guide to Conducting Research in Clinical Oncology*. In addition, SWORG is collaborating with the Behavioral Research Center of the American Cancer Society on a multi-site research study of breast and prostate patients' use of complementary therapies.

Susan Rubin, MA, MBA

Susan Rubin is the Senior Marketing Manager for NASW. The marketing department is responsible for marketing Association programs and projects, overseas the recruitment and retention of members, as well as marketing of the non-dues revenue programs. Ms. Rubin has over 25 years experience in the area of marketing and managing programs in the non-profit sector - both domestically and internationally. She has an MA in history from the University of Texas, as well as an MBA from Georgetown University.

Gina Tesauro, MSW

Gina. Tesauro is a Program Analyst for the Office of Cancer Survivorship at the National Cancer Institute (NCI). She was formerly a Presidential Management Intern (PMI) where she served as an advisor for the 1999 White House Conference on Mental Health in Washington, DC. Ms. Tesauro also served with Vice President Gore's National Partnership for Reinventing Government where she was instrumental in the development of the annual family conference, Family Re-Union 7: Families and Health and related health policy. As part of the Families and Health Initiative she facilitated collaboration between NCI and the Federal Center for Mental Health Services to cosponsor the first federal meeting on the subject of parental illness.

A graduate from The University of Pennsylvania, her clinical experience includes work as an oncology social worker where she developed and implemented therapeutic programs utilizing art, drama, movement and music programs for families coping with illness. Her clinical and personal experience (as a daughter whose mother died of cancer), have deeply influenced her career in public policy.

Nicole E. Vennell, MSW

Nicole Vennell, MSW, is the Management and Communications Coordinator for the Behavioral Research Program (BRP), Division of Cancer Control and Population Sciences, National Cancer Institute (NCI). In addition to her responsibilities for program management and planning efforts, she also coordinates the NCI's Social Work and Cancer Research initiative and serves on the National Institutes of Health Social Work Research Committee. Prior to joining the BRP, Ms. Vennell participated in the Presidential Management Intern (PMI) Program at the NCI and worked in the areas of extramural research, clinical research, human resources, communications, and administrative operations. Ms. Vennell has experience in nonprofit management and mental health services for children and youth. She received her MSW from the University of Michigan.

Gail Woods Waller, MSM

Gail Woods Waller is the Public Affairs Manager at NASW, and currently oversees media relations, public relations, corporate communications, and Web site development strategies for the association. Most recently, Ms. Waller was the communications manager for the Mayor's Office of Employment Development in Baltimore where she led PR and marketing efforts for the \$60 million agency. She has 10 years experience in the workforce and economic development field, and was recognized by the U.S. Department of Labor for coordinating a \$1million corporate-sponsored youth program in her hometown of Kansas City, Missouri. A 1991 honors graduate of the University of Michigan, Ms. Waller began her career in advertising and PR agencies in Detroit. She holds a MS in marketing from Johns Hopkins University, and is an active member of the Public Relations Society of America and the International Association of Business Communicators.

Toby Weismiller, MSW, ACSW

Toby Weismiller is the Director of the Professional Development and Advocacy Division at NASW. As Division Director, she leads the Association's programs in public policy and social work practice, specialty practice sections, government relations, political action, ethics and professional review, international programs, equity issues, and social work credentials and certifications. Ms. Weismiller has served as Interim Executive Director of NASW, and as a board member of the Council on Social Work Education (CSWE). She holds a BA in political science from Purdue University and a MSW from Indiana University. She is a member of the American Society for Association Executives, the Society for Social Work Research, and a member of the Commission on Social Work Practice with CSWE.

Joan Oppenheimer Weiss, MSW, LICSW, LCSW

Joan Weiss, consultant in genetic support, has been the Co-Director of the Human Genome Education Model Project (HuGEM), an internationally recognized genetics education program for health professionals. She currently chairs the NASW working group on standards for including genetics in the clinical practice of social workers. Ms. Weiss is the founding director of the Genetic Alliance (formerly the Alliance of Genetic Support Groups which is an umbrella organization for genetic support groups nationwide). In addition, Ms. Weiss was Executive Director of the Alliance of Genetic Support Groups, Adjunct Instructor at the Department of Social Work, Virginia Commonwealth University and the University of Vermont, Instructor at Georgetown University Hospital and Senior Social Worker in Genetics at the Johns Hopkins Hospital.

Ms. Weiss is a leading spokesperson for the role of social work in genetics. She provides lectures and workshops at universities, hospitals, and at various support group conferences in the United States and Europe. She also serves on several Grant Advisory/Peer Review Committees. A number of national and regional genetic support groups, including the National Marfan Foundation and Neurofibromatosis, Inc. have honored her. She has also received the Knee/Wittman NASW Health/Mental Health Outstanding Achievement Award in 1999 and is listed in *Who's Who of American Women: 2000-2001*, and *Who's Who in America: 2001*. She has published articles in a number of books and journals including: the *American Journal of Human Genetics*, *Journal of Genetic Counseling*, *Health and Social Work*, and the *American Journal of Medical Genetics*. She received her BA from Barnard College and her MSW from Catholic University in Washington, DC.

Tracy Whitaker, MSW, ACSW

Tracy Whitaker is the Manager of the Program, Policy and Practice Department at NASW. Prior to joining NASW, Ms. Whitaker's experience included work with individuals, organizations and community systems. She has served as the executive director of a transitional center serving women who were experiencing homelessness, substance abuse and

mental health issues; as a court monitor overseeing the deinstitutionalization of St. Elizabeth's Hospital and the development of community-based mental health services in the District of Columbia; and as the deputy director of a national resource center which examined and supported women's behavioral health across the life cycle. Ms. Whitaker received her MSW from Howard University and has been with NASW for six years May 1997. She has also served as acting Director of NASW's Professional Development and Advocacy Division.

Joan Levy Zlotnik, PhD, ACSW

Dr. Joan Levy Zlotnik has served as the Executive Director of the Institute for the Advancement of Social Work Research (IASWR) since 2000, working to build social work research resources and to translate research to practice, policy and education. From 1995-2000 she served as Director of Special Projects and Special Assistant to the Executive Director at the Council on Social Work Education (CSWE) serving as liaison to national organizations, universities, foundations and federal agencies in work on aging, child and family, interprofessional and inter-organizational issues. From 1987 through 1994, Dr. Zlotnik worked as Staff Director for the Commission on Families and as Government Relations Associate at NASW. She developed and implemented legislative and regulatory strategies to advocate for prevention and early intervention services for vulnerable children, families, and older persons.

Dr. Zlotnik has been active in promoting partnerships between universities and the practice community. She was the Principal Investigator for the Phase I *Strengthening Aging and Gerontology Education for Social Work* Project at CSWE, and administers a range of grants, contracts and cooperative agreements at IASWR. She is the author of more than 20 monographs, technical assistance documents and scholarly publications.

Dr. Zlotnik has a BA from the University of Rochester, and MSSW from the University of Wisconsin-Madison, and a PhD in Social Work from the University of Maryland.

APPENDIX D

Grant Targets Oncology From January 2003 NASW NEWS

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The National Cancer Institute (NCI) has awarded NASW a grant to find ways to ensure that social workers are educated about cancer research findings and to help develop best practices for oncologic social work.

The grant includes funding for two regional focus groups. Participants will have practice experience ranging from five to 20 years in the field and will identify best practices for such tasks as learning about new assessment tools and new intervention techniques and evaluating intervention.

NASW will also organize a “consensus conference” involving researchers and practitioners and will publish a position paper on the study’s findings. The research will be disseminated through the association’s Web site and its 56 chapters. The findings will also be available for review for continuing education credits for social workers.

“We’re pleased that NCI recognizes the need to explore the methods social workers use to address cancer,” said NASW Executive Director Elizabeth J. Clark. “This grant will allow us to take important steps toward developing effective social work practice.”

Group Explores Access to Cancer Research July 2003 NASW NEWS

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Finding Psychosocial Oncology Research Should Be Easier for Social Workers

A consensus meeting held at NASW on May 6 under a National Cancer Institute (NCI) grant focused on finding ways to improve the distribution of information on best practices in oncology social work.

“Our goal is to help social workers use the existing research and to find ways to overcome barriers to the delivery of this information,” said NASW Executive Director Elizabeth J. Clark, who led the meeting. “We need to make it easier for social workers to find psychosocial oncology research.”

Focus Groups

The May meeting included summaries from two focus group meetings held earlier this year in Florida and California, which were funded by the NCI grant. The focus groups were designed to learn more about how oncology social work research is — or is not — reaching social workers in their daily practice.

Topics addressed by the focus groups included learning-style preferences, such as lectures, written materials or discussions and use of the Internet. The groups also

explored barriers to staying current on relevant research; the two most frequently mentioned barriers were time and access. Some social workers said that increased workloads and staffing cutbacks have lessened the amount of time available to review research findings. Many also noted that it is difficult to access relevant research easily, such as through practice-focused conferences or Web sites.

Among suggested strategies for improving practice-research partnerships, the focus groups recommended cosponsoring research projects among interdisciplinary groups, multi-site research opportunities, development of an updated oncology research bibliography, training seminars on using the Internet to access research and improved access to databases.

Clark said the consensus meeting also addressed the need to promote cancer-related research among social workers. “It’s important to get grant information out to social workers. We should also encourage social workers to be part of research design teams,” Clark said.

Dr. Joan Levy Zlotnik, Executive Director of the Institute for the Advancement of Social Work Research (IASWR), attended the meeting to share a draft of the results of a study IASWR conducted as part of a companion NCI grant. IASWR’s study examined what research is being done by social workers on cancer and sources of research funding.

Zlotnik said that while many social workers are involved in aspects of cancer treatment and prevention work, “few are funded in large-scale studies. There’s a lot of preliminary data that could use further study.”

IASWR’s recommendations included developing social work research opportunities at NCI; developing an NCI social work research agenda and strategy; promoting collaborative social work research and dissemination across the National Institutes of Health and other federal entities; and incorporating research findings and evidence-based practice into social work education and continuing education programs.

The consensus meeting also included a presentation from Dr. Jon F. Kerner, who spoke on translating research into improved outcomes. Kerner is NCI’s assistant deputy director for research dissemination and diffusion.

At the Table

“We must assist in the transfer of knowledge to help get good research out to practitioners,” NASW’s Clark said. “If we’re not at the table when [research studies] are designed, it can affect the applicability of this research. Social workers have a tremendous amount to offer. We know the issues, we know what questions should be asked. But this piece is often missing.”

In addition to Clark, Kerner, and Zlotnik, other NASW and NCI representatives and social workers from around the country attended the meeting. A final report on the consensus meeting is scheduled to be completed this summer.

APPENDIX E

FSOSW MEMBERS PARTICIPATE IN FOCUS GROUP FROM FSOSW PERSPECTIVE

Article written by: Marcia DeSonier, LCSW

Each year billions of dollars are spent on research and hundreds of billions are spent on health delivery programs. Little is spent or known about how research is used to inform practitioners and improve the quality of health care interventions. Generally, knowledge does not translate into practice until a number of other factors, political, institutional, and individual, fall into place.

NASW joined with the National Cancer Institute in trying to understand how we can better and more quickly get current research findings into clinical practice. While the main interest is psychosocial oncology research, they are also interested in all oncology research.

Betsy Clark, Executive Director of NASW, invited FSOSW members to participate in a focus group to try to get answers to questions about how social workers incorporate research into their practice. On February 7, 12 FSOSW members whose years of experience ranged from one or two years post-masters to 20 years in the field of oncology, spent an hour and a half discussing questions that were a part of this project.

The majority of participants felt they were not able to stay current with research finding in oncology. Lack of time was the overwhelming barrier reported to trying to stay current. In fact, they felt it is becoming even more difficult to stay current with the demands of fewer people doing more work. The group felt that brief, easy to understand information on the Internet might help as well as information learned at conferences. While there are numerous journals and sources of information on current research available, there is not time to read them. A few people have been able to incorporate psychosocial research findings to their practice; those that were incorporated mainly dealt with groups for oncology patients. Everyone agreed that evidence-based practice is important for the social work profession and that we must use it to show that we are effective in order to survive. The group also agreed that our interpersonal networks are vital to staying current. All agreed we have to “toot our own horn” and let others in oncology know more about what we do in order to improve the practice/research partnership. And, finally, the group agreed that professional organizations have a major role in helping link research and practice through conferences, newsletters, grants, supporting and participating in research.

FSOSW was pleased to participate in this research project and will look forward to the outcome. A second focus group was held in California. It will be interesting to see how their answers compared to ours. Once the consensus results are known, we will pass them on to our members.