Association of Oncology Social Work

Member Survey Report

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The AOSW Member Survey Report
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Finally, thank you to all of the AOSW members who responded to the survey as the results of this survey will advance AOSW's commitment to developing educational resources and promoting the delivery of quality cancer care to all.

Introduction

Social workers who are members of the Association of Oncology Social Work (AOSW) include some of the most experienced psychosocial oncology experts in the world. AOSW members have designed and implemented model psychosocial programs such as long-term survivor support groups, bereavement groups, and children's support programs. They have published research and clinical practice articles on a vast array of topics such as psychosocial distress related to cancer treatment. They have also been asked to author content for almost every cancer service organization in existence. Now, AOSW is pleased to present the first ever comprehensive survey of its membership.

In 2005, AOSW members completed a survey conducted by the AOSW Social Work Oncology Research Group (SWORG). This report is a result of that survey. This survey collected information that can and will be used by AOSW in a number of ways. First, with this information AOSW will establish an Oncology Social Work online database through which individuals, organizations, and institutions will be able to identify psychosocial oncology experts should they need consultation for patient service programs, authors for patient information materials or web content, presenters for professional education workshops, or trainers.

In addition, findings from the survey will provide the Association with guidance as to the professional education and competency/skill development areas oncology social workers would like to see developed in the future. Finally, responses from the survey offer a profile of the oncology social work workforce, including job demands, case load sizes, and demographics. AOSW is proud of the work of oncology social workers and excited to share this survey with you.

Among a total of 999 AOSW members at that time, 844 members received e-mails regarding survey access through "Survey Monkey". Of these, 535 (63.4%) members completed on-line surveys. In addition, 155 surveys were mailed to members for whom AOSW did not have an e-mail address. Of those receiving surveys through US mail, 87 (56.1%) members returned completed surveys. Overall, a total of 622 members were included in the final analysis, yielding a 62.3% response rate.

Part 1: Member's Expertise and Interests

Practice characteristics

Overall, AOSW members have been in oncology social work for an average of 11 years (SD=7.93, range: 0-50 years). A majority of members are licensed (84.7%), and have an MSW degree (88.9%). In addition, 68.2% of respondents have been a member at National Association of Social Workers (NASW) at sometime in the last five years. Ten percent of AOSW members also are members of the American Psychosocial Oncology Society, and 27 percent are members of the National Hospice and Palliative Care Organization (NHPCO). (See Tables 1-3 below).

Table 1. **The Type of Degree(s) Held by AOSW Member Respondents**

Degree	n*	%
BSW	88	14.2
MSW	551	88.9
PhD	23	3.7
Other	102	16.4

* Multiple responses

Table 2. **Percentage of Respondents Who are Licensed**

Licensed	n	%
Yes	520	84.7
No	82	13.3

Table 3. **Organizational Memberships Held in the Last 5 Years**

Organizations	n*	%
National Association of Social Work (NASW)	422	68.2
National Hospice and Palliative Care Organization (NHPCO)	169	27.3
American Psychosocial Oncology Society (APOS)	62	10.0
Society for Social Work Research (SSWR)	53	8.5
Council on Social Work Education (CSWE)	18	2.9
Intercultural Cancer Council (ICC)	17	2.7
International Federation of Social Work (IFSW)	7	1.1
Other	175	28.3

* multiple responses

※ Other: Social Work Leadership in Healthcare (n=20); The Association of Pediatric Oncology Social Workers (APOSW; n=20); Florida Society of Oncology Social Work (FSOSW; n=8); American Cancer Society (ACS; n=8); other social work oncology local groups, etc.

In terms of primary practice setting, more than half the respondents work in a hospital/clinic/long-term care facility (64.8%), and 57.7% work in urban areas. The majority of members (70.6%) are employed for 40 hours or more per week, and another 18.7% work 25-39 hours per week. On average, members report having 104 client contacts per month (SD 91.6), ranging from 0-800.[1] Approximately 30% of members living in the United States report earning between $45,000 and $54,999 from their primary work setting. Another 31% report earning less, and 36% report earning more. A total of 172 members reported having a secondary practice (i.e., private practice, consultation), and a majority of these members (78.6%) report additional earnings of $10,000 or less from this secondary setting. Members with secondary work settings report having, on average, 18 patients and/or family contacts per month (SD 20.57, range 0-100). (See Tables 4-9.)

Table 4. **The Geographic Location of Primary Practice Work**

Location	n	%
Urban	350	57.7
Suburban	177	29.2
Rural	80	13.2

[1] One member reported having 6,000 client contacts per month, 1 reported 2,000, and 3 reported 1,000. These "outliers" were eliminated from the calculation of the mean and standard deviation to avoid overestimation.

Table 5. **The Type of Primary Practice Setting**

Primary practice setting	n	%
Hospital/clinic/long term care facility	400	64.8
Academic/university health system	102	16.5
Agency or community-based organization	62	10.0
Private practice	61	9.9
Hospice	33	5.3
Mental health/medical office	19	3.1
Homecare	7	1.3
Other	74	12.0

* Multiple responses

※ Other: Ambulatory or comprehensive care cancer center (for outpatients), consulting, free standing clinic, non-profit health organization, support groups, and school

Table 6. **How many hours per week members are employed in your primary practice setting?**

Hours	n (N = 599)	%
Less than 25 hours	64	10.7
25-39 hours	112	18.7
40 hours or more	423	70.6

Table 7. **The Salary from Primary Employment**

Salary	n (N = 594)	%
Less than $25,000	28	4.7
$25,000 - $34,999	46	7.7
$35,000 - $44,999	110	18.5
$45,000 - $54,999	180	30.3
$55,000 - $64,999	120	20.2
$65,000 - $74,999	42	7.1
$75,000 - $85,000	28	4.7
More than $85,000	26	4.4
I am not U.S. Member	14	2.4

The salary from primary employment for non-U.S. Members

: 1.800 Euros / $30,000 / $52,000 CAD / $55,000 AUD / $65,000 AUD / $72,000 AUD / $80,000 / 6,000,000 JPY / 70,000 / 75,000 USD / 80,000 / AUS $72,000

Table 8. **The Type of Secondary Practice Setting (n=288)**

Secondary practice setting	n	%
Private practice	51	8.3
Consultation	32	5.2
Hospital/clinic/long term care facility	21	3.4
Agency or community-based organization	13	2.1
Homecare	11	1.8
Academic/university health system	9	1.5
Mental health/medical office	7	1.1
Hospice	6	1.0
Other	22	3.6

※ Other: supervision (n=3), complementary practitioner, palliative care, US Army Reserve, support groups, etc.

Table 9. **Additional Compensation by Secondary Practice Setting**

Salary	n (N = 145)	%
Less than $5,000	71	49.0
$5,000 - $9,999	27	18.6
$10,000 - $14,999	16	11.0
$15,000 - $19,999	8	5.5
$20,000 - $25,000	9	6.2
More than $25,000	6	4.1
I am not U.S. Member	8	5.5

Additional compensation by secondary practice setting for non-U.S. Member

: $ 0 (n=7) / 450 Euros (n = 1) / $72,000 AUD (n = 1)

Time allocation and measures of competence

Members were asked to report the percentage of time they allocate to various activities and the extent to which they feel competent in those areas. Most members (83%) identified "Direct Service" as the activity in which they dedicate the greatest amount of time. On average, these members indicated that they spend 64% of their time conducting direct service. Ninety-five percent of them indicated a high level of competence. A large majority of members also indicated that their time is spent in patient education (12% of time), program development and/or evaluation (11% of time), , and social work education activities like teaching or training (9% of time). In these areas, 84-91% of members indicated moderate to high levels of competence.

Other areas in which fewer members allot their time include administration (14% of time), providing clinical supervision (5% of time), research (6% of time), community organizing (5% of time), and grant writing (3% of time). In terms of competence levels in each of these areas, and only among those who identify these areas as those in which they allot their time, 25% of 354 members indicated they have little to no competence in administration. Among 313 members providing clinical supervision, 30% indicate little to no competence. And, for the approximately 300 members involved in research, community organizing or grant writing, 63%, 58% and 73% respectively, report little to no competence in these areas. (See Table 10).

Table 10. Work Time Devoted to Practice Areas and the Level of Competence

Areas of Practice	% of time Mean (SD)	N	Level of Competence (n, %)			
			None	A little	Some	A lot
Direct services	64.2% (26.7)	514	1 (0.2%)	1 (0.2%)	26 (5.0%)	486 (94.6%)
Patient education	12.0% (13.3)	418	7 (1.7%)	30 (7.2%)	119 (28.5%)	262 (62.7%)
Social work education (e.g., teaching, training)	9.0% (13.2)	391	16 (4.1%)	39 (10.0%)	133 (34.0%)	203 (51.9%)
Program development and/or evaluation	11.3% (12.4)	378	23 (6.1%)	37 (9.8%)	155 (41.0%)	163 (43.1%)
Administration	13.7% (19.1)	354	32 (9.0%)	58 (16.4%)	114 (32.2%)	150 (42.4%)
Grant writing	2.7% (4.6)	318	96 (30.2%)	135 (42.5%)	66 (20.8%)	21 (6.6%)
Community organizing	4.9% (8.3)	316	52 (16.5%)	130 (41.1%)	82 (25.9%)	52 (16.5%)
Providing clinical supervision	5.4% (8.5)	313	60 (19.2%)	34 (10.9%)	87 (27.8%)	132 (42.2%)
Research	6.1% (14.2)	278	64 (22.9%)	111 (39.9%)	70 (25.2%)	33 (11.9%)

Members also were asked to report the percentage of time they allocate to work with different population groups. Most (76%) of members reported allocating 39% of their time to adults aged 40-64. Slightly fewer members (75%) reported allocating 32% of their time to older adults aged 65-79. Sixty-four percent of members reported allocating 12% of time to the oldest old population group (age 80 and older), and 69% of members reported allocating 15% of time to work with adolescents and young adults. Forty-five percent of members reported working with children (0-14 years of age), and allocating just 3% of time

to practice with this age group. Members reported moderate to high levels of competence in working with these populations.

With respect to non-English speaking populations, 58% of members reported allocating, on average, just under 10% of their time, and 50% of these members indicated that their level of competence in working with these populations was little to none. As for low-income populations, 69% of members reported allocating almost 39% of their time, yet feeling moderate to high levels of competence. A small proportion of members also identified gay/lesbian, homeless, hearing-impaired and veterans groups as populations with which they work. (See Table 11).

Table 11. Work Time Devoted to Each Population for Direct Services and the Level of Competence

Population	% of time Mean (SD)	N	Level of Competence (n, %)			
			None	***A little***	***Some***	***A lot***
Middle adults (40-64)	39.2% (18.2)	475	1 (0.2%)	2 (0.4%)	47 (9.9%)	425 (89.5%)
Older adults (65-79)	32.1% (17.4)	466	1 (0.2%)	6 (1.3%)	50 (10.7%)	409 (87.8%)
Low income populations	39.2% (26.4)	430	6 (1.4%)	18 (4.2%)	101 (23.5%)	305 (70.9%)
Adolescents/Young Adults (15-39)	15.3% (12.0)	425	13 (3.1%)	37 (8.7%)	152 (35.8%)	223 (52.5%)
Oldest adults (80 and over)	12.3% (11.9)	397	5 (1.3%)	16 (4.0%)	87 (21.9%)	289 (72.8%)
Non-English speaking populations	9.8% (12.4)	363	39 (10.7%)	142 (39.1%)	126 (34.7%)	56 (15.4%)
Children (0-14 years old)	3.0% (7.6)	277	59 (21.3%)	73 (26.4%)	89 (32.1%)	56 (20.2%)
Other	6.8% (18.3)	30	16 (53.3%)	1 (3.3%)	3 (10.0%)	10 (33.3%)

※ Other: gay and lesbian (n=5); addiction; hearing compared; homeless, minorities; veterans; hypnosis

Part 2: Roles, Functions and Expertise of AOSW Members

Members were asked to indicate their level of competence across 33 topical areas (Table 12). A majority of members reported very high competence in 17 areas, including personal coping skills (76%), end-of-life issues (77%), self-advocacy (decision making and problem solving) (75%), advance directives (73%), caregiving (65%) and group work (psychoeducational or support group) (60-61%). Areas in which members reported little to no competence include complementary and alternative practices (38%), organizational development (42%), pain assessment and management (34%), creative/expressive therapies (56%), political/legislative advocacy (54%), building private health practice (79%), cognitive behavioral therapy (45%), business skills for human service professionals (66%).

Table 12. **The Degree of Competence Members Feel with Regard to Following Topics**

Topics	Not at all	A little	Some What	Very
End of life issues	1 (0.2%)	15 (2.6%)	114 (19.7%)	450 (77.6%)
Personal coping skills	1 (0.2%)	8 (1.4%)	131 (22.5%)	443 (76.0%)
Self-advocacy (e.g., decision-making, Problem solving)	1 (0.2%)	15 (2.6%)	130 (22.4%)	434 (74.8%)
Advance directives	3 (0.5%)	37 (6.4%)	117 (20.2%)	422 (72.9%)
Grief and bereavement for adult patients & Families	1 (0.2%)	11 (1.9%)	164 (28.3%)	403 (69.6%)
Caregiving	1 (0.2%)	22 (3.8%)	179 (30.7%)	381 (65.4%)
Family issues	0 (0.0%)	15 (2.6%)	184 (31.8%)	380 (65.6%)
Psycho-educational groups or patient education	2 (0.3%)	41 (7.0%)	183 (31.4%)	356 (61.2%)
Stress management	0 (0.0%)	26 (4.5%)	206 (35.4%)	350 (60.1%)
Support Groups	7 (1.2%)	54 (9.3%)	175 (30.1%)	346 (59.5%)
Depression/anxiety	2 (0.3%)	21 (3.6%)	220 (37.8%)	339 (58.2%)
Financial distress and assistance	7 (1.2%)	55 (9.5%)	189 (32.6%)	328 (56.6%)
Survivorship	5 (0.9%)	33 (5.7%)	218 (37.6%)	324 (55.9%)
Discharge care / planning	29 (5.1%)	85 (14.9%)	145 (25.4%)	312 (54.6%)
Ethics	3 (0.5%)	35 (6.0%)	237 (40.9%)	304 (52.5%)
Home health care	5 (0.9%)	94 (16.2%)	182 (31.4%)	298 (51.5%)
Interdisciplinary team leadership	12 (2.1%)	65 (11.4%)	204 (35.7%)	290 (50.8%)
Your country's health care system	8 (1.4%)	67 (11.6%)	289 (49.8%)	216 (37.2%)

Topics	Not at all	A little	Some What	Very
Use of humor in clinical practice	23 (4.0%)	122 (21.0%)	222 (38.3%)	213 (36.7%)
Cultural competence/diversity	2 (0.3%)	66 (11.4%)	300 (51.7%)	212 (36.6%)
Patient navigation	39 (6.8%)	111 (19.5%)	212 (37.2%)	208 (36.5%)
Children whose parents have cancer	20 (3.5%)	143 (24.8%)	230 (39.9%)	184 (31.9%)
Cancer and the workplace/Employment issues	6 (1.0%)	112 (19.3%)	304 (52.3%)	159 (27.4%)
Sexuality	7 (1.2%)	118 (20.3%)	312 (53.8%)	143 (24.7%)
Organizational development (non-profit or for-profit)	61 (10.5%)	181 (31.1%)	214 (36.8%)	126 (21.6%)
Cognitive Behavioral Therapy (CBT)	68 (11.8%)	189 (32.8%)	194 (33.6%)	126 (21.8%)
Pain assessment and management	32 (5.5%)	164 (28.2%)	269 (46.3%)	116 (20.0%)
Complementary and Alternative practices	42 (7.2%)	177 (30.4%)	251 (43.1%)	113 (19.4%)
Grief and bereavement for pediatric patients & families	126 (21.8%)	185 (32.1%)	174 (30.2%)	92 (15.9%)
Creative/expressive therapies (i.e., art, music, etc.)	95 (16.5%)	226 (39.2%)	188 (32.6%)	68 (11.8%)
Business skills for human service professionals	173 (29.9%)	206 (35.6%)	149 (25.8%)	50 (8.7%)
Political/Legislative advocacy	66 (11.4%)	247 (42.8%)	217 (37.6%)	47 (8.1%)
Building a private health practice	294 (51.3%)	156 (27.2%)	78 (13.6%)	45 (7.9%)

When asked to identify organizations for which members have worked as a group facilitator, program coordinator, trainer or board member, more than half of all members indicated having done work in conjunction with the American Cancer Society, and 30% for the Leukemia & Lymphoma Society (Table 13). In addition, members listed other institutions, agencies and programs for which they have done work.

Table 13. Organizations members have worked with as a group facilitator, program coordinator, trainer, or board member

Organizations	n*	%
American Cancer Society	318	51.5
The Leukemia & Lymphoma Society	184	29.8
Cancer Care	130	21.0
Ortho-Biotech	117	18.9
Gilda's Club	99	16.0
The Wellness Community	78	12.6
Other	132	21.4

* Multiple responses
Other: cancer community center, cancer support group, National Cancer Institute, sunstone cancer support centers, cancer care foundation, hospice, etc.

Activities

Social workers are involved in a wide and varied scope of activities that include counseling, case management and system navigation, group facilitation, administration, advocacy, education and research. We asked members to indicate which of these activities they conduct for various population groups, including families, children, survivors, caregivers and bereaved populations (Table 14). More members reported involvement in counseling than any other activity.

Table 14. **Involvement in programs related to each population (N = 616)**

	Counseling	Case management/ navigation	Group facilitation	Admin- istration	Advocacy	Education	Research
Families/ family members	482 (78.2%)	394 (64.0%)	292 (47.4%)	101 (16.4%)	393 (63.8%)	457 (74.2%)	64 (10.4%)
Children	141 (22.9%)	82 (13.3%)	63 (10.2%)	38 (6.2%)	114 (18.5%)	148 (24.0%)	10 (1.6%)
Adolescent /teen population	163 (26.5%)	82 (13.3%)	59 (9.6%)	39 (6.3%)	120 (19.5%)	159 (25.8%)	12 (1.9%)
Young-adults (20s-30s)	408 (66.2%)	341 (55.4%)	215 (34.9%)	86 (14.0%)	331 (53.7%)	368 (59.7%)	60 (9.7%)
Adult	470 (76.3%)	406 (65.9%)	345 (56.0%)	119 (19.3%)	406 (65.9%)	447 (72.6%)	103 (16.7%)
Elderly adult (80 years and older)	415 (67.4%)	379 (61.5%)	216 (35.1%)	96 (15.6%)	352 (57.1%)	374 (60.7%)	59 (9.6%)
Survivorship population	372 (60.4%)	244 (39.6%)	251 (40.7%)	83 (13.5%)	301 (48.9%)	349 (56.7%)	62 (10.1%)
Bereaved populations	377 (61.2%)	193 (31.3%)	161 (26.1%)	63 (10.2%)	206 (33.4%)	301 (48.9%)	33 (5.4%)
Caregivers	468 (76.0%)	310 (50.3%)	245 (39.8%)	89 (14.4%)	333 (54.1%)	428 (69.5%)	52 (8.4%)

Referral Patterns

With regard to referral patterns, members were asked to indicate the frequency to which they refer patients/clients to information, referral and/or service organizations (Table 15). Forty-three percent of members indicate that they refer patients to the American Cancer Society at least every week, 29% indicate that they refer to CancerCare at least every week, and 23% refer to the Leukemia & Lymphoma Society at least every week.

Table 15. **Referral patterns**

Organizations	N	Never	Less than once a month	Once a month	2-3 times a month	Every week	More than once a week
American Cancer Society (or national cancer society)	546	21 (3.8%)	87 (15.9%)	66 (12.1%)	135 (24.7%)	105 (19.2%)	133 (24.2%)
The Leukemia & Lymphoma Society	522	60 (11.5%)	125 (23.9%)	93 (17.8%)	124 (23.8%)	48 (9.2%)	72 (13.8%)
Cancer Care	511	71 (13.9%)	97 (19.0%)	82 (16.0%)	113 (22.1%)	64 (12.5%)	84 (16.4%)
Pharma-sponsored patient support or education	505	128 (25.3%)	110 (21.8%)	75 (14.9%)	88 (17.4%)	42 (8.3%)	62 (12.3%)
National Cancer Institute	500	101 (20.2%)	120 (24.0%)	73 (14.6%)	91 (18.2%)	51 (10.2%)	64 (12.8%)
National Patient Advocate Foundation	485	168 (34.6%)	124 (25.6%)	67 (13.8%)	61 (12.6%)	37 (7.6%)	28 (5.8%)
The Wellness Community	483	202 (41.8%)	97 (20.1%)	55 (11.4%)	58 (12.0%)	28 (5.8%)	43 (8.9%)
National Coalition for Cancer Survivorship	483	178 (36.9%)	141 (29.2%)	70 (14.5%)	51 (10.6%)	23 (4.8%)	20 (4.1%)
Lance Armstrong Foundation	474	188 (39.7%)	145 (30.6%)	49 (10.3%)	50 (10.5%)	20 (4.2%)	22 (4.6%)
Gilda's Club	469	276 (58.8%)	72 (15.4%)	34 (7.2%)	36 (7.7%)	21 (4.5%)	30 (6.4%)
Other 1	171	19 (11.1%)	10 (5.8%)	21 (12.3%)	36 (21.1%)	26 (15.2%)	59 (34.5%)
Other 2	91	12 (13.2%)	7 (7.7%)	14 (15.4%)	22 (24.2%)	17 (18.7%)	19 (20.9%)
Other 3	56	14 (25.0%)	7 (12.5%)	5 (8.9%)	10 (17.9%)	5 (8.9%)	15 (26.8%)

※ Other: Cancer care, cancer hope network, cancer life line, cancer services, children's leukemia foundation, hospice, local cancer center and financial assistance organizations, integrative medicine, health planners, private counseling, school, etc.

Clinical Trials

With regard to clinical trials, almost three-quarters of members (75%) indicated that they engage patients and family members in discussion about clinical trials less than 25% of the time (Table 16).

Table 16. **Frequency of engaging patients/family members in discussion about clinical trials**

Frequent of engagement with patients	n (N = 573)	%
76% to 100% of the time	21	3.7
51 – 75% of the time	48	8.4
26 – 50% of the time	77	13.4
1 – 25% of the time	292	51.0
Never	135	23.6

Program Development and Involvement

AOSW Members have developed and utilized diverse programs for psychosocial assessment and treatment. In particular, they have used screening tools such as BSI-18 or other stress screening inventories for psychosocial assessment (n = 94). Also, many respondents (n = 55) reported that they developed cancer support groups, and encouraged clients to participate for emotional support and education (Table 17). In general, 63% of members reported experience in project/program planning (Table 18).

Table 17. **Psychosocial or prevention/screening programs members have developed**

Programs	N
Use of diverse screening tools/ psychosocial assessment	94
Cancer support groups (online and offline)	55
Cancer awareness education programs / orientation	32
Comprehensive psychosocial support programs (including camps)	19
Outreach program for cancer screening	10
End-of-life and palliative care programs / Bereavement groups	12
Counseling services	3
Patient navigation programs	3
Intensive case management	1
Other specific cancer prevention programs	19

Members also identified a wide range of activities in which they have experience, such as serving on ethics committees (36%), organizational advisory boards (53%), and conference planning committees (48%). In terms of leadership experience, 38% of members indicated having experience as a committee chair. See Table 18 and Appendix 3 for members' experiences across a range of activities.

Table 18. **Activities in which members have experience**

Activities	n (N = 618*)	%
Project/program planning committee	389	62.9
An advisory board	328	53.1
Conference planning	296	47.9
Committee chair	232	37.5
Ethics committee	221	35.8
Quality assurance committee or accreditation review	182	29.4
Fundraising or development committee	163	26.4
Board of directors	148	23.9
Program or research grant review	105	17.0
Cultural competence committee	68	11.0
Institutional review board	61	9.9
Board of trustees	21	3.4
Other	51	8.3

* Multiple responses

※ Other: Cancer committee, journal peer review, new employee education, patient/family education committee, grant writing, hospital palliative care committee, website development, patient satisfaction taskforce, etc.

Part 3: Patient Care

Members were asked to report on the extent to which certain psychological, physical or social conditions served as barriers to receiving quality cancer care. A majority of members identified four items to be major barriers to receiving quality cancer care: fear, depression, anxiety, or distress (53%), inability to pay for treatment-related expenses (63%), inadequate health insurance (67%), and transportation problems (55%). A summary of items, along with the proportion of members who found these items to be barriers (or not) is listed in Table 19.

Table 19. Barriers to patients and families receiving quality cancer care

Barriers	Not a barrier	Somewhat of a barrier	A major barrier
Inadequate health insurance	19 (3.4%)	164 (29.2%)	378 (67.4%)
Inability to pay for treatment-related expenses	19 (3.4%)	189 (33.8%)	352 (62.9%)
Transportation problems	25 (4.5%)	226 (40.5%)	307 (55.0%)
Fear, depression, anxiety or distress	7 (1.3%)	254 (45.4%)	299 (53.4%)
Worries that work wages will be lost to attend a medical appointment	16 (2.9%)	294 (52.7%)	248 (44.4%)
Lack of coordination among service providers	50 (9.0%)	315 (56.6%)	192 (34.5%)
Lack of information or understanding about cancer and its treatment	61 (10.9%)	345 (61.7%)	153 (27.4%)
Denying or ignoring physical pains or symptoms	39 (7.0%)	369 (66.2%)	149 (26.8%)
Lack childcare or eldercare	43 (7.7%)	373 (67.1%)	140 (25.2%)
Language barriers	62 (11.1%)	355 (63.7%)	140 (25.1%)
Lack of information about where to find appropriate care	82 (14.7%)	350 (62.6%)	127 (22.7%)
Other health problems that make it difficult to get to the doctor or hospital	48 (8.6%)	396 (71.1%)	113 (20.3%)
Cultural barriers (e.g., customs, beliefs, etc)	55 (9.9%)	404 (72.4%)	99 (17.7%)
Distrust of health care system	64 (11.6%)	391 (70.7%)	98 (17.7%)

Too much time waiting for an appointment	160 (28.8%)	310 (55.8%)	86 (15.5%)
Being too busy with other life responsibilities (careers, school, care for young children)	84 (15.1%)	395 (71.0%)	77 (13.8%)
Being unable or unwilling to participate in decisions related to one's own health care	82 (14.6%)	410 (73.2%)	68 (12.1%)
Lack of belief that treatment will improve their condition	96 (17.2%)	400 (71.6%)	63 (11.3%)

In addition, members were asked what they think are the greatest challenges/barriers to effectively providing services specifically to ***underserved populations*** (e.g., elderly, ethnic/minority groups)? Responses were similar to that above: Forty-three percent of members indicated that inadequate health insurance is the greatest barrier to receiving quality cancer care. The next four most-mentioned barriers were inability to pay for treatment-related expenses (32%), transportation problems (26%), psychological symptoms or distress (22%), and lack of information or understanding about cancer and its treatment (15%). The ranking of items as they related to underserved populations are included in Table 20.

Table 20. Top 3 barriers to underserved populations receiving quality cancer care

Barriers	n	Rank
Inadequate health insurance	270 (43.4%)	1
Inability to pay for treatment-related expenses	199 (32.0%)	2
Transportation problems	160 (25.7%)	3
Fear, depression, anxiety or distress	136 (21.9%)	4
Lack of information or understanding about cancer and its treatment	93(15.0%)	5
Lack of coordination among service providers	66 (10.6%)	6
Worries that work wages will be lost to attend a medical appointment	61 (9.8%)	7
Denying or ignoring physical pains or symptoms	56 (9.0%)	8
Lack of information about where to find appropriate care	51 (8.2%)	9
Language barriers	50 (8.0%)	10
Cultural barriers (e.g., customs, beliefs, etc)	40 (6.4%)	11
Distrust of health care system	32 (5.1%)	12
Being unable or unwilling to participate in decisions related to one's own health care	21 (3.4%)	13
Lack childcare or eldercare	19 (3.1%)	14

Being too busy with other life responsibilities (careers, school, care for young children)	17 (2.7%)	15
Lack of belief that treatment will improve their condition	10 (1.6%)	18
Too much time waiting for an appointment	9 (1.4%)	19
Other health problems that make it difficult to get to the doctor or hospital	1 (0.2%)	22
Others		
Lack of resources	11 (1.8%)	17
Lack of education	6 (1.0%)	20
Lack of caregivers and psychosocial support	14 (2.3%)	16
Inability or unwillingness to advocate for self	3 (0.5%)	21
Difficult decisions and need for supportive information on a timely basis Legal status Delay in seeking treatment out of fear about being diagnosed with cancer Lack of safety net for people who they are unable to work Lack of time to discuss medical decision making with physician		

In an open-ended question, members were asked what they think community-based patient support agencies (such as the American Cancer Society, Local National Cancer Society, the Leukemia & Lymphoma Society, etc.) should be doing to help eliminate or reduce barriers to care. Analyzed responses were organized into 6 categories relating to (1) enhancing access to services by tailoring services toward community needs, (2) public policy to promote access to health insurance and social work services, (3) education, and particularly as relevant to low income and non-English-speaking communities, (4) overcoming financial issues through income assistance, assistance with concrete needs like transportation and in-home care for the elderly and children, (5) the role of service agencies in terms of promoting interagency collaboration and delivery of seamless services, and (6) the role of service providers in terms of a multi-disciplinary approach to care. (See Table 21).

Table 21. What can community-based organizations do to eliminate or reduce barriers to care?

1) Access to services:
- (a) Make diverse services easier to access (e.g., telephone or internet, translation services)
- (b) Tailor services toward individual communities
- (c) Develop the patient navigation system
- (d) Use volunteers wisely

2) Advocacy
- (a) Advocate for legislation regarding Universal Healthcare Coverage / Insurance Coverage
- (b) Advocate for increase social work service

3) Education
- (a) Advertising: use the media as a way to educate the general public, public information campaigns
- (b) Community outreach: provide understandable information to low income communities
- (c) Provide materials for education in more than one language (solution of language barriers)

4) Financial issues
- (a) Immediate assistance for concrete needs and direct patient services (e.g., transportation and road to recovery)
- (b) Financial assistances for uninsured or low income clients
- (c) Homecare assistance for the elderly and children

5) The role of service agencies
- (a) Collaboration between social service agencies
- (b) Address administrative conflicts in local chapters

6) Regarding service providers
- (a) Have direct interaction with social workers to address barriers
- (b) Hire oncology social workers
- (c) Educate social workers and providers, onsite and through different medias
- (d) Work with instead of against physicians: be more integrated into the healthcare system
- (e) Conduct research to assess barriers and possible solutions, and evaluate the programs

The question on overcoming barriers to care was followed by another open-ended question asking members what they think AOSW could be doing to enhance their ability as social workers to provide quality care services to patients and families. Members felt that AOSW could promote social work through professional education, advocacy for the profession as well as for patients, resource development, networking, addressing financial reimbursement issues and other financial strains experienced by social workers, and the encouragement and facilitation of new oncology social workers. Suggestions within these six categories are summarized in Table 22.

Table 22. What AOSW could do to enhance social workers' abilities to provide quality care services

1) Education

(a) Provide more psycho-educational or clinical intervention workshop/programs
(b) Provide more regionalized trainings, intensive training, local conferences, teleconferences, or on-line training
(c) Provide training in supervision, leadership development, grant writing, and management skills

2) Advocacy and Lobby

For oncology social workers & social work agencies

(a) Continue to promote the value of oncology social workers (e.g., public marketing campaign, higher salaries)
(b) Improve the professional characteristics of the organization
(c) Get insurance companies to offer more psychotherapy sessions
(d) Fundraising and outreach to the social work community to get involved in helping build community resources
(e) Include social workers on review boards for society sponsored research grants

For patients

(a) Encourage more national awareness of political and legislative campaigns to support patients
(b) Lobbying for change in the healthcare system (e.g., advocacy towards universal health care)
(c) Organize funding to assist patients with medical expenses, or prescription costs
(d) Advocate to have written medical information in more languages

3) Resources

(a) Coordinate and make resource literatures (e.g., newsletters, books, journals, tapes, contact number with agencies) easier to access (networking of resources)
(b) Need to conduct research and publish more social work related articles (e.g., evidence-based research, experiences of oncology social workers)
(c) Provide authoritative guidelines about oncology social work (e.g., staffing requirements, salary ranges, role of oncology social workers)
(d) Develop and distribute materials (e.g., handouts) for patients and families
(e) Compile and post on the web-site on ongoing list of various conferences, educational

opportunities, or better outcomes for patients who receive psychosocial support

(f) Have more availability to members who cannot attend conferences tapes or videos of presentations

4) Networking

(a) Promote networking with other oncology social workers

(b) Continue to collaborate with various organizations (e.g., ACS)

(c) the role of director of the region: should have support to organize a quarterly get together or networking meeting

5) Financial issues

(a) Help financial reimbursement for obtaining more credentials

(b) Offer grants for presenters/participants who are lower income

(c) Reduce the cost of the national conference

6) For new social workers in oncology social workers

(a) Provide access to new social workers to attend conferences

(b) More foundation level training for those entering oncology

7) Others

(a) As regards the time of annual conference, both conferences in AOSW and APOSW happen the same week each year. => there can be some dialogue between the two groups.

Part 4: Psychosocial Oncology Worldwide Educational Resource (POWER)

Two hundred and fifty-two (47%) of members indicated an interest in participating in AOSW's *Psychosocial Oncology Worldwide Educational Resource (POWER)* program, currently in development. Another 163 (30%) said they were not sure (See Table 23). Of those who indicated that either they were interested in the program or not sure, these members then indicated their level of interest in working with various population groups and/or in various settings (See Table 24). Of the 415 members who either indicated an interest or were unsure at this time, more than 75% indicated at least some interest in individuals and families, professional associations, business and industry groups, health care organizations, schools and universities, patient advocacy groups and community organizations. Slightly fewer, but still more than 50%, indicated interest in consulting for organizations serving children and religious organizations.

Table 23. **Interests in the AOSW Consultation programs**

AOSW Consultation programs (N = 540)	n	%
Yes	252	46.7
No	125	23.1
I am not sure	163	30.2

Table 24. **Level of interest as a social work consultant**

Group / settings	N	No interest	Some interest	High interest
Individual and families	365	18 (4.9%)	105 (28.8%)	242 (66.3%)
School/universities	346	31 (9.0%)	121 (35.0%)	194 (56.1%)
Health care organizations	353	23 (6.5%)	147 (41.6%)	183 (51.8%)
Professional associations	344	36 (10.5%)	137 (39.8%)	171 (49.7%)
Patient advocacy groups	340	41 (12.1%)	136 (40.0%)	163 (47.9%)
Community organizations	357	35 (9.8%)	167(46.8%)	155 (43.4%)
Business and industry groups	333	84 (25.2%)	137 (41.1%)	112 (33.6%)
Religious organizations	326	100 (30.7%)	148 (45.4%)	78 (23.9%)
Children/orgs. serving children	316	154 (48.7%)	102 (32.3%)	60 (19.0%)
Other	34	20 (58.8%)	4 (11.8%)	10 (29.4%)

※ Other: Complementary or art therapy, integrative medicine program, hospice, rural practices, program development, etc.

Conclusion

Oncology social workers must be knowledgeable about the myriad factors that influence the delivery and receipt of cancer care in the United States and around the world. They also must be present in the places where needs are the greatest, and proactive in the innovation, creation and delivery of relevant and appropriate services to socioeconomically, culturally, and ethnically diverse populations.

To be successful, our profession must take it upon ourselves to see that we are prepared to face new challenges of delivering quality care in the 21st century. This report serves as a frame of reference, a guide for the investment of resources to prepare, train, and advance oncology social workers in their pursuit of excellence in psychosocial oncology.

Practice Competencies

Results of this member survey indicate that AOSW social workers' perceived competencies and strengths revolve around delivery of direct services and patient education, and primarily in hospitals and/or academic medical center settings. However, most adult cancer patients are seen and treated in community settings, where the presence of an oncology social worker is less likely. Meanwhile, most oncology social workers appear to be practicing in high level tertiary settings where patients are spending less time. We must see this discordance as a challenge to our profession in terms of how we can better serve patients where THEY are. Doing so may require strengthening skills, including grant writing, which will facilitate the integration and movement of social workers into communities where the patients are.

Furthermore, we must ask ourselves: are we truly serving the populations most in need? Persons over the age of 65 comprise approximately 67% of all people diagnosed with cancer; yet, our members indicated that just 44% of their work time is devoted to older and elderly adults. Do older adults have fewer needs and thereby require less of our time? Or, are we more time efficient in our work with older folks and thus have more time with younger patients? Has research yet to clearly indicate the specific health and supportive care needs of older adults with cancer, thereby resulting in a lack of an evidence-base by which oncology social workers develop and implement appropriate and relevant services for these individuals? Or, are we to some extent, and for various reasons, not present and available to this population; or worse, not cognizant of their needs? And, with regard to multi-ethnic groups speaking myriad languages: to what extent are we preparing and recruiting new social workers who can speak the languages, walk among various cultures, and address the particular needs of our multi-ethnic, multi-lingual 21st century world?

Barriers to Care

While our members suggest that their strengths lie in delivery of direct services and patient education, they also suggest that the three greatest barriers to receiving quality cancer care have to do with access: inadequate health insurance, patient inability to pay for treatment, and transportation problems. The role for our organization's involvement in advocacy and public policy is great, and social workers must bring their unique perspective and voice to the halls and institutions where policies are debated and prescribed. It is our professional imperative to "be where the client is," and by extension to represent their voices in the places where as professionals we have access and influence.

Clinical Trials

Cancer clinical trials portend significant advances in cancer treatment and reductions in the burden of cancer. Yet, less than 5% of adults diagnosed with cancer are recruited to clinical trials. Often times, and particularly for racial and ethnic minority groups in the US, lack of participation boils down to psychosocial factors over which social workers have some influence. For example, social workers can play a critical role in reframing patients' misperceptions around the "experimental nature" of clinical trials, thereby contributing to an increased likelihood for participation. Yet, three-fourths of our members indicated that they rarely if ever engage patients in discussions about clinical trials.

Community Partnerships

Our members recognize the value that community-based organizations play in promoting access to services, advocacy and education. These organizations are natural partners with social workers in promoting quality cancer care. As individual social workers partnering with community groups, or as professional organizations, partnering represents a new wave and new opportunities not only for social work practice but also for delivery of services to a larger and broader constituency.

AOSW's mission is to advance excellence in the psychosocial care of persons with cancer, their families, and caregivers through networking, education, advocacy, research and resource development Certainly, survey respondents' suggestions as to what AOSW can do to enhance social worker abilities to provide quality care services are consistent with this mission. Our strength as a profession is our desire and ability to help. The ecological framework for understanding and addressing individual and community needs forms the basis of our training and must continue to inform our profession as we more formally discover ways to maximize social workers' presence, visibility, impact and contribution to the care of people with cancer.