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ASSOCIATION OF ONCOLOGY SOCIAL WORK SURVEY SHOWS MORE THAN HALF OF CANCER PATIENTS SAY CANCER COSTS NEGATIVELY IMPACT THEIR FOCUS ON RECOVERY

66% of Patients with Major Financial Challenges Suffer Depression/Anxiety, 29% of Patients Delay Filling Prescriptions Due to Financial Pressures, and 22% Skip Doses According to Study

December 2, 2009, Philadelphia, PA - New data being released today by the Association of Oncology Social Work (AOSW) demonstrate the extraordinary financial hardships that often complicate or compromise a patient's battle against cancer. Sixty-three percent of oncology social workers surveyed said that financial issues reduce patients' compliance with their cancer treatment – even though that treatment is key to their recovery. Forty percent of patients reported depleting their savings, while almost 30% reported dealing with bill collectors. More than half of patients and caregivers (54%) with a major/catastrophic financial burden said that it has become more difficult to afford treatment for cancer in the past year.

“Managing the costs of cancer treatment is difficult for many patients and families coping with cancer, and may cause distress and worry and make it more challenging to follow their doctors' prescribed treatment course,” said Carolyn Messner, president of the Association of Oncology Social Work.

The survey results are part of an ongoing effort by the Association of Oncology Social Work to increase understanding and support for people with cancer and their families. AOSW was formed in 1984 and is dedicated to the enhancement of psychosocial services to people with cancer and their families to help them cope with the practical, financial, emotional and social concerns of living with cancer.

More than two-thirds (68%) of cancer patients and caregivers surveyed reported that the patient is experiencing financial hardship due to medical bills, and 55% of all cancer patients surveyed say the stress of dealing with costs negatively affects their ability to focus on their recovery. Statistics are based on a new national study of 169 cancer patients, 131 caregivers and 153 social workers.

“Our survey findings demonstrate that the number of cancer patients dealing with financial concerns about their care, especially out-of-pocket costs, is on the rise,” said Mary Ann Burg, Social Work Oncology Research Group Director, AOSW. “The data also show that social workers are well trained and experienced with helping patients and their families find the resources and support they need to cope with cancer, especially the growing financial burdens associated with living with cancer.”

Although most patients report experiencing cost-related psychosocial stresses that social workers are adept at helping manage, only one-third (34%) of patients report actually utilizing a social worker as a resource.

Findings show that nearly all cancer patients, including those with blood cancers such as multiple myeloma, consider effectiveness before all other factors when determining their treatment plan and rank the cost of treatment last in their decision-making process when initially diagnosed. However, new data show that the stress related to finances can impact compliance and potentially present serious consequences. Consider these statistics from the survey:

- Treatment costs negatively impact the ability to focus on recovery for 87% of patients with catastrophic/major financial burdens due to cancer treatment, and 75% of these patients constantly worry about financial issues due to cancer treatment
- Almost half (46%) of patients who have experienced a financial burden from their cancer have cut back on necessary expenses, such as food, to pay for cancer treatment
- 24% of respondents indicated that they suffered a relationship issue in their efforts to afford cancer treatment
- 6% sold a home or relocated due to the financial stress, and 3% had their homes foreclosed
- 56% of patients with a financial burden were not at all prepared to handle the financial burden of cancer, while only 7% indicated they were completely prepared for it

“Ideally, we would not burden catastrophically ill cancer patients with large co-payments for their treatment,” said health economist Louis Garrison, Ph.D., University of Washington. “Out-of-pocket cost shouldn’t be a major factor in cancer treatment selection, but they are an issue that many patients now face and are often a consideration and a component of treatment discussions.”

Only 36% of patients have discussed the cost of treatment with their oncologist, and only 16% of patients and caregivers report that they believe their oncologists give a lot of thought to the financial implications of treatment they prescribe. In fact, only about half of patients feel comfortable speaking with health professionals about financial issues.

Sixty-nine percent of social workers see themselves as cancer patients’ primary resource when dealing with the financial concerns of their cancer treatment. The majority of social workers surveyed indicated that they have a significant impact in helping oncology patients handle their cancer-related financial problems.

“Social workers can help patients reduce overall stress related to cancer treatment costs and care, but not all oncology settings employ social workers, and few employ sufficient numbers of social workers to allow for all patients to have sufficient access to the full range of supportive care social workers can provide,” adds Burg.

Other important survey facts:

- Half of all caregivers agree that they try to shield patients from the financial aspects of cancer treatment
- Social workers report that relapsed patients have a much better understanding of the treatments and medications covered by their insurance versus newly diagnosed patients, signaling that the more that patients deal with their insurance plans, the greater their understanding of their treatment options.
- Multiple myeloma patients are spending almost twice as much on prescription drugs as the average cancer patient

Methodology and Participation

The survey was developed by Kelton Research in conjunction with Millennium: The Takeda Oncology Company under the guidance of the AOSW.

The patient survey involved 169 cancer patients recruited from high-quality online panels and was conducted online from October 23rd to November 1st, 2009. The patient survey took respondents an average of 12 minutes to complete. Fifty-six of these patients have been diagnosed with multiple myeloma, a cancer subset that was researched on behalf of Millennium Pharmaceuticals.

The caregiver survey involved 131 caregivers of patients diagnosed with cancer who were recruited from high-quality online panels and was conducted online from October 23rd to November 1st, 2009. The caregiver survey took respondents an average of 13 minutes to complete. Forty-four of these caregivers take care of a patient with multiple myeloma, a cancer subset that was researched on behalf of Millennium Pharmaceuticals.

Patient and caregiver results are presented in aggregate. Average patient age is 58.9 years, and 59% are dealing with newly diagnosed cancer and 41% are relapsed. The average caregiver age is 50.8 years, and 58% of caregivers are the significant other/spouse of a cancer patient, 16% are a parent, 16% are the child, 8% are other family members and 2% are a friend. Thirteen percent receive treatment at home, 56% receive treatment at a medical office/hospital, and 25% receive treatment at both. The overall margin of error for this study is +/- 5.6% at the 95% confidence level. Margins for subgroups are slightly higher.

The social worker survey participants were from the AOSW membership list. All AOSW members received an email from an AOSW board member asking them to participate; participation was completely voluntary. The online survey was fielded from October 30th to November 20th, 2009.

Social worker respondents have worked with oncology patients for an average of 13 years, 74% work with more than 100 oncology patients each year, and 93% were female. Sixty-four percent indicated that they worked with patients before treatment, 96% during treatment and 71% post-treatment. The overall margin of error for this study is +/- 7.9% at the 95% confidence level.

About AOSW

The Association of Oncology Social Work (AOSW) is a non-profit, international organization dedicated to the enhancement of psychosocial services to people with cancer and their families. Created in 1984 by social workers interested in oncology and by existing national cancer organizations, AOSW is an expanding force of psychosocial oncology professionals. For more information on AOSW please visit www.aosw.org or call 215.599.6093

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