COSA leads the charge against financial toxicity

A COSA working group taking the lead to address the financial toxicity of cancer hosted a breakfast symposium on Friday to preview an evidence-based draft roadmap they have been working on since 2020.

People at the well-attended breakfast were given an opportunity to provide input on the roadmap before it is presented to the COSA Council early next year.

The working group has 17 members and is chaired by Professor Raymond Chan and Megan Varlow. They have defined toxicity as: “The negative patient-level impact of the cost of cancer. It is the combined impact of direct out-of-pocket costs and indirect costs and the changing financial circumstances of an individual and their household due to cancer, its diagnosis, treatment, survivorship and palliation, causing both physical and psychological harms, affecting decisions which can lead to suboptimal cancer outcomes.”

“Financial toxicity is common,” said working group member Professor Louisa Gordon.

“Financial distress can be higher than for the cancer itself.”

Cancer was more expensive than in the past and would become more expensive in future, she said.

In addition to the cost of tests and treatment, the burden extended to patients and their carers losing income.

Varlow, Director of Cancer Control Policy at Cancer Council Australia, said the roadmap was a plan for the entire cancer-care sector, including clinicians, allied health professionals, hospitals and government to try to improve outcomes.

“We see a role for everybody involved in cancer care to do advocacy of some kind. It might be advocacy in your own hospital to think about how to ensure informed financial consent.”

She said there was also a need to advocate to governments and social services.

Chan said: “I don’t think for a moment that it is going to be easy for us to address financial toxicity. But as people who are passionate about this issue, we cannot take no for an answer.”

Gordon shared data from an online survey involving 277 health professionals, including oncologists, social workers and nurses, who work regularly with patients across a broad range of cancer types.

She said a high proportion of respondents reported having patients with financial difficulties.

Respondents generally...
More focus needed for people receiving treatment for incurable cancers

MORE focus is needed on the growing groups of people living with treatable but generally incurable cancers, Director of the Australian Cancer Survivorship Centre Professor Michael Jefford said on Friday.

He said Australia has more than 1.2 million cancer survivors living with or beyond cancer, including an unknown amount with disease that is rarely cured but can be treated to manage symptoms, slow progression and extend lives.

The Peter MacCallum Cancer Centre medical oncologist told a COSA/UICC plenary on the cost to cure that extended survivorship meant clinical care, policy and research priorities may need reconsidering.

"People are living longer with metastatic cancer; many are unclear about their prognosis and plans for ongoing care and there is a lack of focus on survivorship needs of those with metastatic cancer," he said. "The Australian Cancer Plan (launched at the ASM) is an opportunity for greater focus locally."

Newer therapies prolonged survival but could leave patients with significant ongoing symptoms, side-effects, psychological concerns and financial burdens.

People with metastatic cancer needed resources to help with decision-making around work and managing finances due to significant financial toxicity, Jefford said. A review found half of advanced cancer patients with solid tumours and haematological malignancies named loss of income and extra expenditure due to the disease as their area of highest unmet supportive care need.

Jefford said care plans needed to detail follow-up, supportive care and role clarification between community and hospital providers. Healthcare providers needed education on survivorship and supportive care needs of those with metastatic cancer, and new models of care were needed to combine expertise from survivorship, palliative care, primary care and rehabilitation.

Clinical practice guidelines were needed on survivorship care for those with advanced cancer.

His team’s recent paper on the evolving landscape of metastatic cancer survivorship might be a starting point to consider these issues including advocacy to raise awareness and policy-level prioritisation of metastatic survivorship, Jefford said.

Non-oncology healthcare providers needed education on effects of treatment advances on prognosis as many may not be aware of impacts of newer therapies, such as immune checkpoint inhibitors, significantly improving prognosis for previously difficult to treat cancers such as metastatic melanoma and lung cancer.

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FROM PAGE 1 agreed with the statement: “I feel it is appropriate in my role to discuss any financial concerns my patient has."

However, many respondents lacked information on supportive services or resources to facilitate a discussion around financial concerns.

McLoone shared qualitative findings from the survey.

"The main message is that there is not enough time in a typical consultation to discuss financial matters and there are not enough resources to refer to," she said.

Clinicians’ reasons for raising financial issues included a desire to understand barriers to treatment, patient preferences, levels of comfort with costs and ensure informed consent.

Social workers felt that discussing financial issues was a fundamental component of their role, she said.

Nurses felt that they were most accessible to patients, so it was important for them to have discussions.

"While some respondents felt the focus of the consultation should strictly be on the cancer and its treatment, with a referral service for financial distress, others came in strongly for a cross-disciplinary approach and defined responsibility for care givers who come into contact with patients at any stage," said McLoone.

"That said, social workers were perceived to be the health professional with the greatest expertise."

Most non-social worker respondents felt it was their role to identify financial stress in their patients and then to provide onward referral to social work services.

McLoone shared what she described positive, can-do steps.

"If you are comfortable talking about it, your patient is going to feel comfortable talking about it."

"People will appreciate any acknowledgement and support that you give them. We can provide counselling around distress. We can provide education around the normality of financial toxicity in cancer care. We can raise the topic early and make financial toxicity a routine point to discuss."

Summing up, Varlow said: “We know there is power in collective action, so it’s very much about making sure that all of us are working towards solutions.”

"I encourage COSA members to have a look at our working group website and to provide us feedback on the roadmap because we are really keen for everybody to be involved."
Koczwara makes impassioned plea for improved access and survivorship

PROFESSOR BOGDA KOCZWARA closed off COSA’s 50th Annual Scientific meeting with a moving and inspiring Presidential Address in which she used the parable of the Four Horsemen of the Apocalypse as an analogy for how the “cancer apocalypse mirrors life”.

The former COSA president paid tribute to her mentors, to the great cancer innovators of the past 50 years and to Flinders University, which had found a way to accommodate her when she arrived in Australia in 1983 as a refugee from Poland with one year of medical school under her belt.

Noting that there are 100 million cancer survivors alive today, she raised the challenges of survivorship and expressed gratitude for the opportunity to be part of her patients’ stories.

“I have seen my patients marry and divorce, become parents and grandparents, change jobs, move countries, make movies and publish books,” she said.

“Back in the ’60s and the ’70s, we thought that the answer lay in the drug that makes the tumour go away and then everything will be fine. Today, we know that things are so much more complicated.

“While cancer can be seen as a biological entity, the experience of cancer is intrinsically personal,” Koczwara said.

“It was Melburnian Dr Nathan Cherny who pointed out that beyond precision medicine there is personalised care. This recognition has really facilitated advances in personalised care in particular populations, be it geriatric oncology, adolescent and young adults, or paediatric oncology. And we are finally beginning to recognise the unique needs of First Nations Australians in delivery of care to them, with some amazing national champions, said Koczwara.

However, she longed for the day when COSA would recognise patient advocates as members. “They are experts in what life with cancer is all about.”

Another theme of her wide-ranging address was the need for COSA’s leadership to adequately reflect that the majority of members were women.

Koczwara shared her thoughts on the four horsemen from the Book of Revelations, which have been used to personify Death, Famine, War and Conquest.

• Death: “The fear of death is what makes cancer such a dreaded illness. Paradoxically, to escape death we need to focus on life, even if it feels completely impossible. Yet, as oncologists, we tend to talk about reduction in mortality as if it were a measure of good life. When are we going to start routinely measuring the life we live after cancer, the quality of life, and how well people with cancer contribute to society? That should be the measure of our success.”

• Famine: “In oncology, we tend to offer feasts for some and famine for others. We can custom-make a novel treatment for one person, but only if that person has the right means. The issue of access to drugs and treatments does not get the plenary sessions. We do not need feasts for some, we need daily bread for all.”

• War: “In cancer, we tend to glorify war because it’s a war on cancer. We glorify the idea of a triumphant warrior, forgetting the trauma and the burden of being one. We glorify the warring approaches where competition is chosen above cooperation. But there are downsides to competition that breed disparity and distress. The competition between state versus federal leads to cost shifting. The competition between private and public leads to problem shifting. The competition between service providers and academia leads to a lack of vision. And the patients, they get stuck in the middle.”

• Conquest: “The power differentials in our society are all-pervasive and they affect every aspect of our relationships with patients and colleagues. As healthcare providers, we control access, information and actions. What if the patient could get their drugs over the counter? Email you directly, change their own appointments as easily as ordering a pizza. Wouldn’t that be interesting?”

As a global community, she said cancer professionals tended to fall back on the old habits of the rich and powerful by dictating how information and resources flow. “What if we could develop partnerships with other countries that are truly bilateral? We can learn much about innovation and grace and grit with which other countries face the challenge of cancer in much more difficult circumstances.”

Concluding her address, Koczwara said: “As cancer professionals, we can push back the four horsemen by focusing on life and hope with humility, respect for others and the spirit of collaboration and cooperation. But we should also show grit and determination to fight for those who are forgotten, neglected, and without voice. These same qualities apply to the organisations that we belong to and the societies in which we live.

“So happy birthday COSA. Your track record shows the grace and grit of the 50 years as a leader in cancer in Australia. “COSA has promoted knowledge supported research, collaboration, advanced policy and advocacy in Australia and internationally. Many of the current research and policy issues have been spearheaded by COSA from rural cancer centres to financial toxicity. In this complex and very messy world, this work is even more important than ever.”
Working together to reduce impact of medicine on the planet

FRIDAY morning's plenary chaired by Council Victoria's Brigid Lynch showcased examples of how hospitals are decarbonising and improving climate resilience.

In his presentation, University of Melbourne Associate Dean in Sustainable Healthcare Forbes McGain explained that 70% of healthcare emissions are from clinical activities.

"About 20% of the healthcare sector’s carbon footprint appears to arise from pharmaceuticals. And about another 10% stems from medical equipment (single use materials) so oncology has an impact on these two major factors," said McGain. As an anaesthetist and intensive care physician at Western Health in Victoria, he acknowledged that theatre and ICU were also carbon hotspots.

McGain said 150 Australian hospitals recycled IV tubing into garden hoses and many were also reducing nitric oxide gas.

Positive environmental practices at Western Health includes recycling fluid bags. The healthcare group is also transitioning back to reusables and uses environmental footprinting for anaesthetic gases and common equipment. Environmental footprinting calculates the environmental performance of a product or service from cradle to grave.

McGain said avoiding waste was at the top of the waste hierarchy at Western Health. Next came reducing and reusing items if possible. The last resorts were recycling and landfill.

"This is the best way Australian healthcare can become high value and low waste, along with choosing wisely and promulgating best value care."

Clinicians could make a difference by avoiding unnecessary pathology and radiology testing, keeping patients out of hospital, and considering telehealth where feasible.

While some clinicians in oncology were achieving high value, low-waste care, there were no systemised plans in place in Australia.

"Doctors have a role in being advocates for their patients, science and our future. Do something, do it now, involve clients, patients, executives, governments," he pleaded.

"Walk the pathway; 'meat's a treat,' fly to half as many conferences."

Other speaker and delegates gave examples of green practices, such as recycling blister packs, switching from IV to oral antibiotics and changing event catering to vegetarian.

Sydney Children’s Hospital pharmacy director, Dr Felicity Wright, said syringes took over 1000 years to biodegrade. Therefore, the hospital had reduced full blood counts (FBCs) for every cancer patient to 48-hourly unless needed more often. This reduced waste and saved $300,000 annually.

Dietitian Dr Stefanie Carino, of the Climate and Health Alliance, said half of Australian and New Zealand health services had joined its free Global Green and Healthy Hospitals program. She encouraged delegates to join, view its global roadmap for healthcare decarbonisation and gave examples of hospitals converting to green practices and saving hundreds of thousands of dollars.

Monash Sustainable Development Institute Associate Professor of Practice in Planetary Health Dr Angie Bone urged system change, such as phasing out care that does not help patients. Clinicians were key to driving change, she said. So services should find green champions.
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