

Helping the media to get the message

→ Peter McIntyre

How do you report on an issue that is publicly taboo and personally sensitive, and where the data are scant and the professionals can be unhelpful? Seven journalists who gathered at the UICC conference in July found they could learn a lot from one another.

There is a smattering of applause in the airy press room of the Washington Convention Center as today's headlines ticker across the bottom of the television screen. CNN has picked up the news that a billion people will develop cancer this century, unless something is done.

Around the room, journalists are filing stories from the World Congress of the International Union Against Cancer (UICC). Some of these journalists work for media in Africa, Asia, Latin America and Central Europe, countries where up to 70% of new cancers occur, but where cancer is often seen as a non-issue.

This mismatch prompted three organisations to support health journalists from these countries to attend back-to-back conferences in Washington DC in July – the UICC World Congress, and the Health or Tobacco Conference – to develop their knowledge.

The American Cancer Society

(ACS) the European School of Oncology and the UICC selected journalists from daily newspapers, TV, a news agency and a specialist magazine:

- Jacqueline Montes Eguino, reporter for *La Razon* newspaper in Bolivia
- Kristina Baxanova, reporter for bTV Balkan News Corporation, Bulgaria
- Ashraf Amin, assistant head of the science desk on *Al-Ahram* newspaper, Egypt
- Yaa Oforiwah Asare-Peasah, deputy news editor of the Ghana News Agency
- Viktoria Kun, reporter for *Nepszabadsag* newspaper, Hungary
- Conrado Generoso, editor in chief of the *Medical Observer*, in the Philippines
- Timothy Makokha, deputy health editor of *The New Vision* newspaper, Uganda

All these journalists know that cancer is highly significant in their countries, but is given little priority compared with HIV/AIDS, TB, malaria, diabetes, and diarrhoea.

Public awareness of cancer is low, while fear and stigma inhibit discussion. The journalists accept that the media must bear some responsibility.

Jacqueline Montes Eguino says: "The media is not doing its job. We do not have enough articles talking about cancer. People with cancer don't have access to surgery or medicines and, unfortunately, they just die. In rural areas people think they can use traditional medicine and a poultice."

Most people seek treatment far too late, and so, says Timothy Makokha, cancer is seen as "one disease that consigns you to an early death". Viktoria Kun agrees. "If you say 'cancer', most people understand 'death', but when you know about this subject you can face it much better."

JOURNALISTS LACK ACCESS TO DATA

If journalists are to play their part in combating fear and stigma, they need access to facts and to experts. When



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On the job. The seven sponsored journalists filed stories to their newsrooms from the UICC and Tobacco or Health conferences. The trip provided an ideal opportunity to find out more about cancer, and to discuss with colleagues about how to improve media coverage of the disease. *From the left:* Jacqueline Montes Eguino (Bolivia), Conrado Generoso (the Philippines), Kristina Baxanova (Bulgaria), Timothy Makokha (Uganda), Rennie Sloan from the American Cancer Society, Ashraf Amin (Egypt), Viktoria Kun (Hungary), and Yaa Oforiwah Asare-Peasah (Ghana)

journalists lack access to basic information, this contributes to one-dimensional reporting that stokes public alarm rather than improving awareness.

Conrado Generoso says: "Journalists who write for the tabloids or television often get their facts wrong and give people wrong information. The health community has to help to train journalists on health reporting so they can understand what doctors talk about and translate the stories into something the layman can understand."

Kristina Baxanova believes that the media often tells only one side of the story – failing to highlight the benefits of treatment and prevention. "In Bulgaria most people understand this as an incurable disease. Most stories we cover are about bad examples. We also need to cover good examples of how to prevent or cure or talk about cancer."

But it can be difficult to find the

facts. From Uganda, Makokha complains of "stifling bureaucracy, unnecessary secrecy and a deliberate unwillingness to give information". By the time a journalist has obtained permission to access information, the deadline for the story has often passed.

Official information is of suspect quality. Generoso says: "In the Philippines even data on cancer incidence is hard to get from government health agencies – and is often outdated. There is no centralised agency that collects data and makes them available."

Ashraf Amin points out that in countries like Egypt, with no national screening programme, data about cancer are often derived only from patients seen at national hospitals or from WHO estimates. In Bolivia, too, the pattern of disease is clouded. "There is no official information or statistics about cancer cases, because most of them are treated by the pri-

vate sector or by traditional medicine," says Montes Eguino.

ETHICAL ISSUES

Journalists, just like doctors and nurses, face ethical problems daily, with pressure put on them from outside forces, and by a natural tension that exists within journalism between the need to make headlines and the need to protect people from harm.

There is a particular problem when companies or individuals promote drugs or treatments, and even responsible reporting can fuel demand which poorer countries have no way of meeting.

Kun, who won an ACE (Awarding Cancer Enlightenment) award for her articles about the situation in Hungary, sees a need to balance stories about scientific advances with an understanding about the availability of treatment. "I have ethical problems because there are many people who

cannot access these medicines. Recently, a professor came to Hungary and was 'selling' a story about a wonder drug. I was against publicising this because it puts a wrong idea into the heads of patients. But I could not do anything. They saw this on TV as a wonder medicine."

Amin points out that journalists are not in a strong position to know who provides good treatment and who is making extravagant claims. "The media has a problem because many people claim to have cured cancer. And sometimes people's cancer does seem to have been cured. We are not doctors and we are not able to say what is scientific and not scientific, and the doctors themselves are not that confident about it."

Another issue is the extent to which it is right to use individual human stories to make articles about cancer more interesting.

Generoso encourages his journalists to humanise stories with the consent of the individual and their doctor. "Don't tell me that 8,000 people die of breast cancer. Find me one person and put a face to the story." To some extent, says Viktoria Kun, this can benefit the patient. "Often people say that they feel better because they could speak to someone." Yaa Asare-Peasah believes that human stories also help people make good choices. "We have to tell the story to explain why you should go to the doctor."

But Montes Eguino does not agree, and her paper, *La Razon*, does not use individual patient stories in this way. "Of course it makes more impact to use one case, but we don't do that in my paper. We write about the situation generally, not about individuals."

Amin sees another dilemma. "I am ashamed to say that rich and powerful people do not appear on our

screens; it is just the poor people who do not have the means and facilities. The NGOs put patients on the media to get more money. We take pictures or show how a mother is suffering. The patient did not really have a choice. They have been used. I do not know if it is ethical or not."

Television reporter Baxanova believes that journalists face a difficult choice. "There is still a lot of stigma attached to cancer. Patients are often shy and afraid to talk. I show the back of the head, or interview the doctor. But if we want to influence people and be more effective, you have to show people. If you show only statistical data and doctors, it is not easy for the audience to understand."

SCIENTIFIC LANGUAGE BARRIERS

There are technical problems for journalists in non-English speaking countries, as most research material is in English, and reporters need a high level of skills to access this, to understand and to explain it in their own languages.

Amin, who writes for a mass-circulation Arabic paper in Egypt, says that this can lead to conflict between journalists and doctors: "Most journalists do a double job as journalists and translators, searching for the easiest term for the readers and giving the scientific meaning for the doctors. Most scientists want to see it in the paper with all the scientific details. As a journalist, we have to make it readable. Sometimes the text is accurate but not readable. Or sometimes journalists do their work and make it readable, and scientists refuse to be interviewed and say that media people are not accurate."

These issues are poorly understood by doctors and nurses, who often steer clear of the media and

have little confidence in dealing with journalists. But by working with journalists, they can affect the way that cancer is reported.

CHANGING PRIORITIES

Certainly, Baxanova felt that her own priorities had changed from intensive exposure to global experts at the Washington conferences. "I can show that if we can treat cancer early, we can have incredible results. I was very interested in the vaccination programmes. I think I should be stronger in fighting to do stories on these issues."

Asare-Peasah said it had broadened her horizons. "I have done health reporting for many years, but this has been an eye opener. It makes me think that in Ghana we are far behind on a cancer control programme. I am going to focus a lot more on cancer issues in the future. Media reporting is very poor compared to other health issues."

For Generoso, the conferences highlighted an imbalance in global news coverage. "We get the news through news agencies about breakthroughs in the developed world, but very little about what is happening in Africa. That was an eye opener. We hear about AIDS and malaria, but I did not realise that cancer was a big problem there."

Amin believes that journalists can help countries to learn from each other. "I was very touched by the presentations from Africa, as if we were in the 18th century while others were talking about new technology. The main message I come away with is that people are denied treatment and services because of lack of resources. We should be learning from each other and how to help each other. Maybe we don't listen to each other enough."