

# Stigma: breaking the vicious circle

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**Stigma breeds silence, which fuels the fear and ignorance that feeds the stigma. Breaking this vicious circle not only makes life easier for people with cancer, but can also change public attitudes towards prevention and early detection, as some recent campaigns have shown.**



**I** learned that a person with cancer is a person and must be helped.” This statement is one among many similar recorded in an impact assessment of a two-year campaign to change public perceptions of cancer, spearheaded by the LiveStrong foundation. It testifies to the success of the campaign, but it also speaks volumes about prevalent attitudes that many people will find all too familiar: being diagnosed with cancer leads some people to see you as less than the person you were; they may avoid you, or feel ill at ease with you, or even behave in a hurtful or discriminatory way.

This is stigma. It deeply unfair to people who already have a difficult disease to cope with. But stigma also

plays a toxic role at a wider social level, helping make cancer and cancer patients invisible, stifling informed public discussion and perpetuating a cycle of fear and misinformation that blocks attempts to raise awareness about avoidable cancer risks and the importance of early detection.

Many people argue that policies and programmes to tackle this stigma – and the misinformation that it feeds off and perpetuates – are essential if we are to turn back the rising toll of suffering and death from cancer. Claire Neal, part of a team that heads up the LiveStrong anti-stigma campaign, is one of them. “Challenging stigma is a key that opens a lot of doors across the entire cancer control continuum,” she says. “In our experi-

ence, if you can remove that barrier you can increase access to services and increase effectiveness of health promotion messages.”

## Why the stigma?

A few years ago, the LiveStrong foundation spent a year interviewing more than 4500 healthcare providers, cancer survivors, organisational leaders and community members across 10 countries, to learn more about cancer stigma and how it operates (*Cancer Stigma and Silence Around the World: A LiveStrong report*). They concluded that it is pervasive, existing across countries, cultures, and communities, and is characterised by a set of feelings, attitudes and behaviours, that they have compiled



into a universal “stigma index” that includes views such as:

- Treatment and support are useless for someone with cancer
- I would feel uncomfortable being friends with someone with cancer
- People can only blame themselves for getting cancer
- I would feel isolated/alone if I received treatment for cancer
- If my spouse had cancer, I would consider leaving him/her.

Neal believes there are a number of reasons why being diagnosed with cancer carries stigma in a way that, for

instance, developing meningitis, measles or malaria doesn’t. Cancers can affect a person in so many ways – how they look, how they feel, their sexuality, their ability to have children, and often relationships with friends and family. “There are so many ways that cancer and its treatment can impact a person’s life, and there has been this silence around it,” she says.

Uncertainty about how and why it develops is another factor. “Cancer is less well understood, because it is so many different diseases. Often we don’t know exactly what causes it,

and this can lead to different interpretations of what brings it on.” In many communities it can be seen as the result of witchcraft, or a judgement from God, says Neal. In others it can be attributed to stress, to having a negative mindset or to failing to take proper care of one’s mind and body. “Our research has shown that people often believe that people with cancer brought it on themselves, which again can be very stigmatising.”

Fears that the disease may be infectious can result in people being shunned by friends and neighbours and

SHUTTERSTOCK

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excluded from the community. Fears that it is hereditary can ruin the marriage chances of those with a mother or father known to have had cancer. Whole families can find themselves impacted, which can then put intolerable strains on relationships, leaving people with cancer even more isolated. Stories of men walking away from marriages when their wife gets cancer – or vice versa – seem to be common across the globe; the concept of “relationship-toxicity” is now circulating among parts of the advocacy community as one of the common side-effects of cancer.

### A cancer control issue

Not surprisingly, such negative beliefs, attitudes and behaviours can make people reluctant to ‘admit’ that they have cancer, or even that they are worried they may have cancer. They may be deterred from seeking professional advice about worrying symptoms or from attending screening – particularly if they are ill-informed about the value of picking up and treating cancers at an early stage. Another result, says Neal, is that it becomes very hard to challenge the stigma and misinformation, which then creates a vicious circle. “Because people feel stigmatised they don’t want to talk about it. And in not talking about it, a lot of myths and misconceptions are increased and allowed to perpetuate.”

Breaking that vicious circle by challenging myths about cancer was adopted by the Union for International Cancer Control (UICC) as its campaigning focus for this year’s World Cancer Day. It was an interesting

exercise, says Caroline Perréard, who played a key coordinating role, because myths are shaped by specific realities and cultures, and the campaign had to be relevant for all 760 member organisations in 155 countries.

UICC chose to focus on four myths:

- Cancer is a death sentence
- It is a matter of fate – nothing can be done about it
- It is a disease of the wealthy, elderly and developed countries
- It is only a health issue.

And they asked member organisations to identify the myths most relevant to them and to adapt the messages to their own needs.

It wasn’t clear how effective this approach would be, not least because the countries most in need of promoting conversations about cancer myths would be those where the taboos and silence are strongest. “Working with different regions is very challenging, because there are different messages that we need to get across,” says Perréard. “It’s a learning curve. We want to aim messages to all regions of the world. But messages need to get to countries like Japan and Korea, for instance, where stigma is such a big issue that it is very hard to communicate about prevention or myths. People don’t have access to the information.”

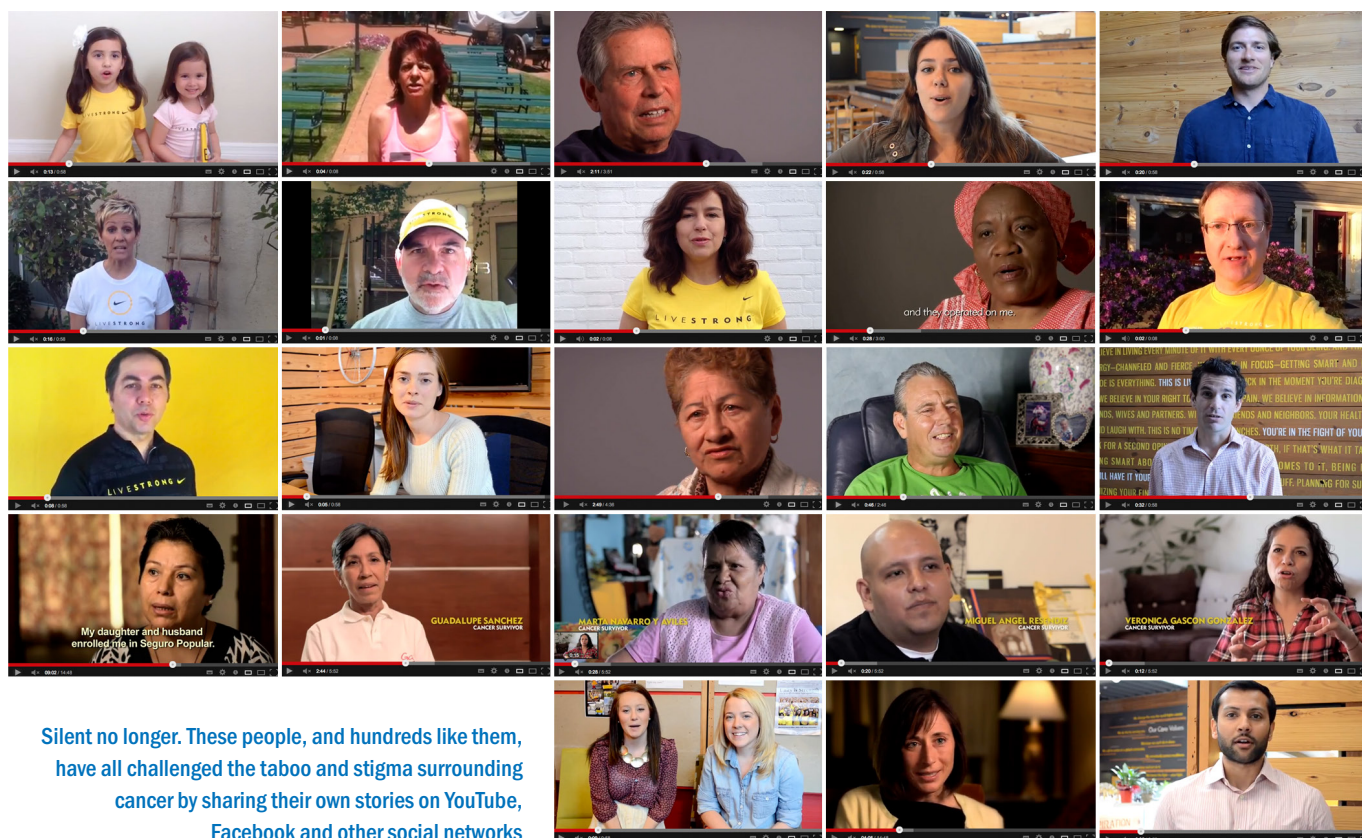
Perréard was surprised by the feedback from member organisations. “They were really thrilled,” she says. “They were so pleased to have a single theme they could all unite behind.” Groups with a long track record of advocacy on stigma and myth-busting used World Cancer Day to stage ral-

lies and capture the media spotlight. Groups that rarely venture into this territory took the opportunity to open conversations about the prevalence and nature of misconceptions about cancer in their communities, getting medical students to do interviews with one another and/or members of the public, which were then shared on YouTube or other social networks and used in press conferences. The authority given by this international focus helped create the conditions for survivors to break the silence and tell their stories, to show that cancer does not have to be a death sentence, that early diagnosis is important, and that even when it can’t be cured, with treatment, care and support you can still have a good life.

An interactive map of events on the UICC’s [worldcancerday.org](http://worldcancerday.org) website gives an idea of the range of actions carried out around the globe. Click on Jeddah (west coast of Saudi Arabia), for instance, for an impressive example of how the UICC’s global message was adapted to a local audience (“Myths and misconceptions about breast cancer”, Wardi video).

### More similar than different

Looking at the issues highlighted across the globe, it is the similarities that really stand out. People in developed countries may be less likely to blame witches, or even God, for their cancer, but they nonetheless show a strong tendency to distrust conventional medicine and turn to unproven and often irrational therapies when cancer strikes. And while progress in early diagnosis and treatment has reduced fear and stigma



Silent no longer. These people, and hundreds like them, have all challenged the taboo and stigma surrounding cancer by sharing their own stories on YouTube, Facebook and other social networks

associated with breast and cervical cancer in countries with more developed health systems, the same cannot be said of lung cancer, which remains hard to detect in time even in richer countries, and still carries that burden of fear.

The vicious circle also seems to operate in a very similar way across the globe. A systematic review of the impact of stigma and nihilism on lung cancer outcomes, published in *BMC Cancer* in May last year, offers a pertinent example. It showed that perceptions that a diagnosis of lung cancer will inevitably result in death,

and that cancer cannot be effectively treated, lead to delays in taking symptoms to the doctor or to refusing recommended treatments and investigations. Lung cancer carries a particular stigma due to its association with smoking, and the study found that this too could lead patients to delay reporting symptoms, because they believed that “treatment for lung cancer would likely be denied to smokers,” or that they would be “blamed for their disease”, even if they didn’t smoke.

The study also found that patients’ sense of being stigmatised acted as a

deterrent to attending support groups – effectively leaving them silenced and invisible, and making it harder to challenge prevailing prejudice and convey potentially life-saving messages – the vicious circle at work again.

### A joined-up approach

Further complicating this picture is the potential of anti-tobacco campaigns to reinforce this stigma, and thereby contribute to delayed diagnosis and added suffering for patients. A survey of attitudes towards lung cancer patients, conducted for the Global Lung Cancer

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Coalition in 16 industrialised countries across five continents (Ipsos MORI 2011), showed the most negative attitudes were recorded in Australia – a country that has led the world in its efforts to tackle smoking – with 29% of respondents expressing agreement with the statement “I have less sympathy for people with lung cancer than people with other types of cancer.” This compares with only 14% in Spain and 10% in Argentina (where the least negative attitudes were expressed). Evidence cited by the *BMC Cancer* study, meanwhile, indicates that some people with lung cancer see information campaigns on tobacco as “contributing to fatalistic views, as they focused on death rather than treatment” and that they feel the press reinforces the smoking-related stigma.

This potentially counteractive relationship between prevention and early detection messages may also work in the reverse direction: efforts to reduce the fear and stigma that can deter people from seeing their doctor need to take onboard the potential impact on prevention efforts. This seems to be the message coming out of a comparative study of perceptions of cancer in France and Morocco that was commissioned by the French Ligue contre le cancer and published to coincide with this year's World Cancer Day. The study showed that while French and Moroccans both associate “illness” and “death” with the word “cancer”, the French respondents were far more likely to mention treatment, for instance “chemotherapy”, while the Moroccans were more likely to talk in

terms of a “danger”, or a “red zone that must be avoided”. However, the more positive French perception of the disease was accompanied by a far less accurate perception of lifestyle risks. More than 80% of Moroccans identified tobacco as the biggest cause of cancer, compared with less than 70% among French respondents, and while Moroccans put alcohol as the second most important avoidable risk factor (45%), French respondents put alcohol into fifth place at 31%, rating it as less important than pollution (38% vs 29% of Moroccans) and genetic factors (37% vs 23% among Moroccans).

Taken together, these findings indicate the need for a joined-up approach to cancer control where different aspects reinforce rather than undermine each other.

### Breaking the vicious circle

Fighting stigma and fear is not traditionally a key component of national cancer control policies, but evidence of the impact where it has been done well suggests that perhaps it should be. The LiveStrong foundation recently completed two pilot anti-stigma campaigns – one in South Africa and one in Mexico – which hinged on giving cancer survivors a platform to tell their own stories. They seem to have achieved their objectives in the short term at least.

The impact assessment of the Mexican campaign showed that three out of four people exposed to the campaign learned something new about cancer; almost an equal proportion said they now talked more openly about cancer;

and more than two in five said they did something different – in terms of protecting their own health and/or being more supportive to people with cancer – because of what they had learned.

Fernando Rodriguez helped organise the Mexican campaign. “At the beginning of the campaign, we had information from many different countries about why people don't receive the proper treatment on time,” he says. “The problem is they never go for check-ups because they are afraid of learning they have cancer. Part of our objective was to try to change people's opinions. Instead of using awful numbers about all the people dying of lung cancer or prostate cancer or breast cancer, we tried to use the stories of all the survivors, from different social, economic and cultural backgrounds, and with different kinds of cancer. The idea was that, if they got together to speak out, they could help reduce the fear, break the silence and give different information through different approaches.”

One thing they learned from survivors early in the campaign is that the fear and misperceptions are not only deterrents to early diagnosis, but also result in patients failing to complete their full course of treatment, “because they feel awful and feel it is part of dying a little bit.” So the campaign tried to address this, says Rodriguez, by promoting the concept of ‘the new normal’. “You will have critical changes maybe, but after the treatment you can have a new normal life. A lot of people say you have cancer, you are superhuman. No, I am not superhuman. I am different because now I can appreciate the

simple things of life. But you don't have to go down this path to learn to enjoy your life like me. That is part of the message from cancer survivors."

Focusing on four major cities in Mexico, they used radio, television, newspapers and, crucially, social networking. Two- to three-minute videos in which survivors from all ages and backgrounds gave their stories were uploaded onto the "Share your Stories" Facebook page. The site soon became a forum where survivors were able to interact with one another and upload their own videos. By the end of the campaign, the page was getting almost 900,000 visits per month.

In a stroke of genius, the campaign co-opted the support of Mexico's popular wrestling stars. They staged well-publicised events that started with the traditional good-guy-versus-bad-guy format. Two masked interlopers representing cancer would then enter the ring, and the good guy and the bad guy would team up to defeat them, with the whole crowd behind them. "The whole point was about the stigma," says Rodriguez. "The good guy and the bad guy were on the same team. Whether you are good or bad you are both wrestling the cancer."

Government support for the campaign, as an effective way to raise awareness about cancer and convince people to use the screening and treatment services available, was crucial. "People don't want to go because they are fearful and superstitious. We served as a link between those services and the public," says Rodriguez. Mobile screening clinics attended the pub-

lic events, and people were also able to pick up tickets to attend clinics for check-ups. Where the results showed further investigations were needed, says Rodriguez, they were referred on to the relevant clinics or institutes.

The government also cooperated in an initiative to help health workers communicate better with patients and the wider public about cancers. This involved community health workers and hospital staff – nurses, admin workers, even oncologists. Now that the pilot is over, government and campaigners are keen to find ways to carry on work that they feel has proved so effective, says Rodriguez.

"We weren't sure if it would work, particularly as these were short-term campaigns," says LiveStrong's Claire Neal. "But we've been really encouraged to see that, yes, in a short amount of time, by elevating the voice of survivors, we were able not only to affect people's perceptions of cancer, but actually change what they did. More people were going to get screening, they were talking more openly about cancer, they were changing what they were doing as a result of these campaigns. We had hoped we would see perceptions shifting, but I think we found much more than that."

Most encouraging of all, says Neal, is the enthusiasm among participants to keep the campaigns going after the end of the formal pilot. "In both South Africa and Mexico local partners have said that they want to continue the activities of the campaign, and that they had reached populations they had never reached before."

In Mexico, Rodriguez is busy with a follow-up campaign based on photographs, called "Before cancer, After cancer", to carry the message that "the cancer could be another chapter in your life." He is also talking to the government about continuing support for the communication workshops, and maybe other parts of the campaign. "They want to encourage survivors to continue these activities, to speak out and share their stories of cancer. And at national level they are very interested in workshops for healthcare providers," he says.

LiveStrong is hoping the "stigma index" and the toolkit that they have developed will be used by groups across the world. "We see an incredible opportunity in this kind of work. If you can change how people view cancer you can really have an impact," says Neal. "What I think we've seen in the mental health community and HIV/AIDS and other areas where stigma is an issue is that often we focus solely or largely on access, but it has to be done at the same time as addressing stigma, because if there is this great stigma, people aren't actually accessing what's there. So the two have to go hand in hand."

The UICC also is keen to find ways to continue this work. The 16 member organisations that are on the Advisory Group that plans and organises World Cancer Day have agreed to stick to the same theme for 2014, focusing on new myths to dispel. Caroline Perréard is looking forward to it, saying the enthusiasm among the UICC members makes it the most exciting campaign she has worked on. ■

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