



STIGMA & SILENCE: A LIVESTRONG BRIEF

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ABOUT THE RESEARCH: In 2007, LIVESTRONG executed a global research study to better understand how cancer is portrayed and perceived around the world. We looked at multiple sources of data—including media coverage, public opinion surveys and semi-structured interviews—across Argentina, Brazil, China, France, India, Italy, Japan, Mexico, Russia and South Africa.

Stigma is a primary reason why people affected by cancer do not receive the care they need.

Through 18 months of global research, LIVESTRONG discovered that cancer continues to carry a significant stigma worldwide. However, we found many opportunities to capitalize on shifting perceptions. And even though awareness of prevention, early detection, treatment and survival are on the rise, too many people still say they feel uninformed about cancer.

Other lessons learned:

- When facing cancer, people worldwide want information and emotional support for themselves and their families.
- By directly combating stigma and creating an arena for cancer survivors to share their experiences, we can increase awareness, remove barriers to cancer-care access and begin to change the impact of this disease.
- Communication is critical to decreasing cancer-related stigma, raising awareness and spreading

WHAT DO PEOPLE THINK ABOUT CANCER AROUND THE WORLD? THE LIVESTRONG STUDY FOUND A RANGE OF PERSPECTIVES, FROM PESSIMISM TO RESOLVE AND EVEN HOPE.

"Cancer is a death sentence."

 INDIA

 "Cancer is a **nightmare** for the people."

 ITALY

 "Cancer is perceived as a tragedy."

 JAPAN

 "It's a constant threat."

 "There are **no preventives**."

 MEXICO

 "Long drawn-out process of **hurt**."

 SOUTH AFRICA

 "Cancer is a sword that hangs over our heads."

 "I think about **fear, death and loneliness**."

 "Nothing you can do about it."

 "What comes to mind when I think of cancer is **silence**."

 "**Pain** is the first word that comes to my mind."

 "It terrifies me. **It's sly**; it's not always easy to foresee it."

 "The cancer patient suffers a lot of **isolation**."

 "The first thing that comes to my mind is **imprisonment**."

 "I think about an ugly disease, an awful beast."

 "If you get treatments early enough, they say you should be ok... **it could also be the end**."

 "Getting cancer doesn't have to be the end because there are **effective treatments**. I think of it as a preventable illness."

 "I think of death and struggle, but also **perseverance and strength**."

 "If I get it, it wouldn't be the end of the world."

 "It certainly cannot be prevented 100% of the time, but we can **cut the risk of cancer**."

 "More and more people are recognizing it is treatable."

 "Just because you have cancer doesn't mean you will be unhappy."

 "People are not scared about the disease anymore, because today, **in every family, there is someone who has had cancer**."

"We can beat cancer." 

education. Multiple mass media channels are key education resources, as are people with a personal history of cancer – especially well-known or celebrity survivors.

- School systems have strong potential for cancer education. Increasing cancer awareness among children may be a valuable investment.

Based on our study, **LIVESTRONG** offers the following calls to action:

1. Where we can raise awareness of existing cancer-fighting tools, we need public education and resource campaigns to directly address cancer-related stigma.
2. The global cancer community should leverage these positive shifts to create effective media campaigns and behavioral interventions to help increase survivorship.

What is LIVESTRONG doing to help end stigma and silence?

LIVESTRONG is acting on the results of this research to strengthen patient advocacy. In 2008, we launched the **LIVESTRONG** Global Cancer Campaign, culminating in the landmark 2009 **LIVESTRONG** Global Cancer Summit. We brought together more than 500 world leaders, corporations, non-governmental organizations and advocates – all working to reduce the burden of cancer in their own communities. Since then, our efforts have been focused on empowering people affected by cancer and advocating for governments to support anti-stigma efforts.

2010 saw the start of two **LIVESTRONG** pilot projects in South Africa that we hope to use as a model worldwide:

- A joint effort with John Snow Inc. (JSI), our Anti-Stigma Initiative is the first of its kind in the world. The initiative seeks to show that survivors can lead healthy, productive lives during and after cancer, and encourages both personal and public dialogue about the disease.
- A collaboration with the American Cancer Society and local partners, the Survivor Empowerment Initiative supports national calls to action by empowering survivors to become cancer-control advocates and preparing cancer organizations to plan and host a Survivor Forum.

LIVESTRONG also supports key policy initiatives at the global, federal and state levels to improve the lives of people affected by cancer. Civil society organizations can support efforts to reduce cancer stigma by implementing educational programs and awareness-building efforts. They can also create support systems for patients and families, along with a health system that provides access to care for all and that supports compassionate end-of-life care.

Quick facts:

- 28 million cancer survivors worldwide
- One-third of all cancer incidents are preventable and one-third are treatable with early detection and proper resources
- Cancer is the number one killer around the world – claiming more lives than tuberculosis, HIV/AIDS and malaria combined
- 8 million people will die from cancer this year
- More than 70 percent of all global cancer deaths occur in low- and middle-income countries

ABOUT LIVESTRONG

LIVESTRONG serves people affected by cancer and empowers them to take action against the world's leading cause of death. Created as the Lance Armstrong Foundation in 1997 by cancer survivor and champion cyclist Lance Armstrong, the organization is now known publicly by its powerful brand – **LIVESTRONG** – and is a leader in the global movement on behalf of 28 million people around the world living with cancer today. Known for its iconic yellow wristband, **LIVESTRONG** has become a symbol of hope and inspiration to people affected by cancer around the world. Since its inception, the organization has raised more than \$400 million for the fight against cancer. For more information visit LIVESTRONG.org.

TO READ OR DOWNLOAD THE FULL **CANCER STIGMA AND SILENCE REPORT**, VISIT LIVESTRONG.ORG/STIGMA. OR REQUEST A COPY BY EMAILING RESEARCH@LIVESTRONG.ORG.

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