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Palliative care needs communication

Ladies and gentleman,

Palliative care needs communication. Communication between health care professionals, between health care professionals and politicians, between health care professionals and patients. If we talk about palliative care, communication is needed everywhere.

I would like to give you some ideas about only one, but important problem: How can we improve the knowledge among the public about what palliative care is, and the benefits it can offer patients and health systems? And how could we get the journalists on side, especially newspapers-journalists, to help us make things better. What we know is that medical and health issues in the media are often highly relevant at a personal level to the general public because issues have distinct effects on individuals, families and well-being.

Let me give you some examples about media-coverage and palliative care: In Germany the legal claim of specialized outpatient palliative care exists since 2007. But the ambitious goal of full coverage in peoples homes has still not been

achieved. People, who decide to die at home are still at a great disadvantage when it comes to receiving palliative care, especially in rural areas.

The problems of palliative situations in life are not highlighted enough within our society in general. There is a requirement for increased availability of information. Once informed, consumers want to be able to have access to palliative care if they need it. They say that they would be very likely to consider using palliative care if they or a loved one would have a serious illness.

A few days ago we had the yearly congress of the German Cancer Society. And once again speakers pointed out: Eleven years after the legal claim there are still too many people who wish to die at home, but don't have the chance.

If you would have tried to find anything about the problem in nationwide newspapers after the end of the congress, you would have found nothing at all, the nationwide German media doesn't care.

It doesn't mean that we cannot find stories about palliative care in German newspapers, but they are often highly politicised and far removed from reality.

A second example, not about palliative care, but comparable, about cancer and the end of life:

In summer 2016, the German TV and radio presenter Miriam Pilhau died at the age of 42 years.

She was very popular in Germany. In 2008 a breast cancer

had been found. She could defeat him – that's, what the media told. In 2012 she became a mother. In march 2016 she professed to be previously diagnosed with lung cancer. Also this disease seemed defeated. In early summer 2016, she published a book, and the key message was: I have beaten cancer. Interviewed by a german radio station, she said: "I am healthy, you can say that (...). The word miracle was at my doctors because it was an absolutely improbable development. According to statistics, it would not give me today."

Two or three weeks later Miriam Pielhau died, and the whole nation asked: How could that happen?

For maybe two or three days the story of Miriam Pielhau was the most discussed news-information in Germany. And not only that. The media spoke about women with metastatic breast cancer. Experts explained, that problems of these women are totally different, if you compare their situation with women, who for the first time have been diagnosed with breast cancer.

Two or three days later, it was all over. Nobody talked about Miriam Pielhau any more. Nobody talked about breast cancer.

Australian singer and actress Kylie Minogue was a superstar with the world at her feet, when at the age of 37 she was diagnosed with breast cancer.

News coverage caused an unprecedented increase in bookings for mammography in Australia later. Researchers

from Sidney and Melbourne examined women over 40 who booked mammograms as part of the Government's BreastScreen programs in the 19 weeks before, the two weeks during and the six weeks after the publicity surrounding Minogue's illness. Overall bookings for breast screening increased 40 per cent in the two weeks of Kylie-related publicity. Six weeks after the publicity, mammography bookings remained nearly 40 per cent up in previously unscreened women. (1)

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A discussion started, if health advocates should develop anticipatory strategies for responding to news coverage of celebrity illness. I personally think, that it really could be useful to discuss this strategy. This is my key-message: We have to learn that it is not up to us to make the rules of the game. It is the media that makes the rules.

There is often a dissatisfaction about media coverage on the part of medical researchers and practitioners. They tend to compare the style, tone, and quality of media stories with those of articles in medical and health research.

„Information in medical and health scientific journals is based on scientific communication logic designed to inform about explorations of potential advancements and scientific debates. It is theoretically informed and evidence-based.“

But what's the idea of journalism? I found a good explanation from british communication scientists: “The

logic of news is to report on contemporary events, developments, debates, and conflicts in society. It is concerned with what is really new, what affects the public, and whether social institutions are effectively addressing public challenges. It has a critical stance towards all authorities – including science, medical, and health institutions – and its logic is based on holding power to account and finding and reporting different perspectives on issues. The style of presentation in media is designed to be engaging, lively, and entertaining.” (2)

What do the media like?

- Stories with audience appeal
- Issues that stimulate debate, controversy, or conflict
- Stories that create higher ratings and larger audiences
- Fresh angles or twists on issues that will attract public interest
- Accurate background information.

What do the media dislike?

- Covering old topics

- Duplicating stories reported by competitors
- Poorly written, spammy press releases
- Receiving numerous calls when on a deadline.
- People who persist when a story idea is rejected
- Organizations that believe their story is interesting simply because it is theirs or that convey the attitude that the importance of the story is obvious. We will leave this congress and we all know more than before how important palliative care is. But there are rules: it is up to journalists to decide whether our message is important enough to be published in newspapers.

Social media

Social media have created global networks with power to quickly spread information, mobilize high numbers of people behind a cause. “This technology can also be used by health professionals to: improve patient-physician interactions, enhance patient motivation, drive awareness, provide accurate information, raise timely issues, facilitate the exchange of ideas, frame and reframe health-related questions, engage a larger community.” (3)

The online world, in particular, is alive with discussions,

comments about the topics of illness, disease, hospitals, death and dying.

There are inherent challenges with the use of social media, but also major opportunities. What we need are careful discussions: How can the media help to disseminate the palliative care message to a global audience? There is no silver bullet to success; it takes time and strategie, there is still a long road to go.

1. Simon Chapman, Simon Holding, Kim McLeod and Melanie Wakefield: Impact of news of celebrity illness on breast cancer screening: Kylie Minogue's breast cancer diagnosis. *Med J Aust* 2005; 183 (5): 247-250.

2. Robert G. Picard and Minhee Yeo: *Medical and Health News and Information in the UK Media: The Current State of Knowledge*. Dezember 2011, Reuters Institute for the Study of journalism, University of Oxford

3. Daniel R. George, Liza S. Rovniak, Jennifer L. Kraschnewski; Dangers and opportunities for social media in medicine. *Clinical Obstetrics and Gynecology*. 56(3):453–462, SEP 2013