

SHOULD YOU LIE TO YOUR GRANNY?

When it comes to healthcare there are different opinions about patient care East and West, and as market researchers, understanding this is critical. Yvette (Wei-Yu) Ke from THE PLANNING SHOP explains why



In Changchun, China, a family discovers their Nai Nai (grandmother) has been diagnosed with terminal cancer and seemingly only has a short time to live. Their discussions are instinctive: “If you tell her, will you ruin her good mood?”. Their conclusions: “Yes”.

The family decide to keep the diagnosis from Nai Nai and instead hastily arrange a wedding for a grandson who has only been in a relationship for a few months. The wedding is pitched as a chance for a family reunion, but in reality, it's an excuse for a final farewell. Nai Nai is excited, and completely unaware that the benign shadows on her scans are anything but and foretell a fatal end.

Does this sound like a Hollywood drama? It should because it's the plot for a much-talked-about new Hollywood movie called 'The Farewell'. However, it's not just a film as this happens all the time in parts of East Asia, including Japan and Singapore.

For many in the Western world it may come as a surprise that a family could do such a thing, but having grown up in Taiwan, this scenario is neither surprising nor unusual. If I were to knock on my neighbours' doors back home, it would be easy for me to find a family going through a similar scenario. In fact, it even happened to my family...

Back in 2013, when my grandmother was diagnosed

with colorectal cancer at the age of 89, a family meeting was called to discuss what to do next. If we told our grandmother the truth, she would no longer enjoy her twilight years: meeting friends, playing with her grandchildren and celebrating important festivals and events. She'd also become sensitive to how she looked, what she ate or how much she slept. As a family, we knew we had a responsibility to keep her away from these worries, and a duty to carry the burden for her.

As we are very 'Xiao-Shun', we decided not to tell her. We agreed to arrange the surgery to remove the malignant tumour in her body, without telling her what the surgery was for.

It fell to my mother to take the lead. She told grandmother the check-up was fine, but the doctor had recommended a small operation to remove bowel polyps. She did not mention the 'big C' at all. I was in two minds at the time. I'd been brought up to believe in the importance of being honest, but I also believed we must show our 'Xiao-Shun'.



Two weeks before the surgery, we took our grandmother to hospital to discuss pre and post care. The surgeon, anaesthetist, radiologist, nutritionist and case manager were all there. When we saw them, the first thing we did was hand over a slip of paper that said, “Our grandmother doesn’t know she has cancer”, just in case any of them leaked our secret. The surgery went ahead.

My grandmother will turn 95 this year and she is particularly proud that amongst her siblings she is the only one who has never had cancer! To this day she still doesn’t know the truth. Maybe this belief is one of the reasons she’s alive and well.

Why am I telling you this story and talking about ‘The Farewell’? Because, as a global healthcare market researcher, I believe it’s important to understand different cultures, and what drives patient care across a variety of societies, nations,

traditions and backgrounds. How can we ever understand the needs and drivers for different treatments and pharmaceutical products unless we truly understand the decision-making processes and who makes those decisions?

What are the other differences?

As a Taiwanese living and working in London, I’ve experienced how Western culture puts greater emphasis on the individual, their personal freedom and right to privacy, and how this is different from the Eastern way of collectivism, family focus and harmony.

With family playing a central role in Eastern culture, family-based decision-making happens for all parts of life, not just healthcare and treatment choice. In my grandmother’s case, our family was heavily

‘Xiao-Shun’ translates as filial piety – or more simply put respecting your elders and looking after them. Traditionally, there is a lot of pressure and criticism from society if you don’t demonstrate ‘Xiao-Shun’.



involved in the decision-making process. From which doctor she needed to see, the need for and type of surgery (minimally invasive or traditional with an implant) and post-surgical care. Despite the fact my grandmother was competent enough to make her own choices, she happily followed our decisions. Especially as there is satisfaction and honour to be had in being protected by the children she spent her entire life taking care of.

Studies suggest 30-50% of cancer patients in China have a diagnosed condition concealed from them and over half of family members consider withholding a cancer diagnosis from the patient.

(Footnotes 1-3)

Aside from cultural taboos, insufficient legal framework and a lack of awareness of patient rights, this statistic is fuelled by other socio-demographic factors. Families are often afraid to cope with a patient's emotional reaction or they may simply be unable to afford recommended treatments.

In China, physicians tend to go along with non-disclosure requests from families to avoid patient conflict and even violence. Several cases exist where doctors have informed patients of their diagnosis, without the family's permission, and have then been reported or faced legal action.

Violence towards medical staff is also an issue, on average 27 such attacks are reported in each hospital in China every year (with countless others not reported or settled with pay-offs). Violence in China's healthcare system is another story in itself, but you can begin to understand why physicians are often willing to cooperate in non-disclosure agreements with family members. (Footnote 4)

References:

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4. 'Under the Knife: Why Chinese patients are turning against their doctors.' Christopher Beam, The New Yorker, August 18, 2014

In Western society it seems inconceivable that patients would not be told this type of information. Occasionally we hear of requests from family members to withhold information from patients – particularly when they become substitute decision-makers closely involved in patient care. However, patient autonomy is entrenched in Western healthcare systems. This notion triggers several ethical issues and not to mention the legal and civil implications.

This contradiction poses an interesting challenge in truly understanding patient experiences and how we leverage these for global brands and patient support initiatives.

Change is coming

Over the next few decades I expect things in Asia to change. With an increased level of awareness about patient rights in younger generations and new legislation emerging, this culture of non-disclosure will certainly evolve. In January 2019, Taiwan passed the 'Patient Right to Autonomy Act', the first country in Asia to introduce this type of law. Many hospitals in Japan also self-regulate that patients should be informed of their diagnosis unless they have agreed otherwise.

There's also a lot the West can learn from the Asian model. In fact, we're beginning to see Western systems increasingly adopt the concept of patient and family-centred care. This does not mean patients are deprived of making their own healthcare decisions, but the aim is to promote the importance

of family members' roles in the patient's healthcare experience, improving patient outcomes and support plus greater satisfaction for healthcare professionals.

One size never fits all

Patient experiences are complicated, subject to constant change and highly dependent on healthcare systems, the services available, culture and society. In healthcare market research we often see US and European-based companies applying a Western-centric perspective to the rest of the world. This lack of understanding of some aspects of Eastern culture could lead to research outcomes that do not fit with local practices, which in turn creates gaps when trying to draw one global patient experience.

Eastern countries are now promoting patient-centric care to balance the heavily involved family element, and the West is starting to integrate family decision-making and support. It's interesting because this means differences in patient experiences should become less pronounced over time with a convergence of Eastern and Western values.

For now, though, we must never forget the considerable importance of understanding the impact of differing cultures, customs and traditions when devising and interpreting healthcare market research solutions.

P.S. If you ever meet my grandmother, please don't tell!



About the author

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She began her pharmaceutical consultancy and market research career in Taiwan where she built up her strong knowledge in Asian markets. Since then she has extended her career in the UK to develop her experiences across global markets.



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