

Silent Questions

(Not) Talking about Dying in the Pearl River Delta

Mira Menzfeld

Received: 6 April 2021; Accepted: 16 September 2021; Published: 28 April 2022

Abstract

This Field Notes contribution describes the difficulty of confronting the topic of dying in conversations with terminally ill persons in the Pearl River Delta region in the People's Republic of China (PRC), and how the ethnographer responded to this difficulty in a way she did not expect. While there is probably no ideal conversation starter for this subject anywhere in the world, bringing up the topic of approaching death is particularly challenging in China. First, it is considered impolite and harmful to communicate to a person directly that she is dying. Second, a terminal diagnosis is not necessarily received as though fatality is an inevitable consequence. After more than a few instances of feeling awkward and unequipped to talk to terminally ill persons during fieldwork, the author came to a realisation: encouraging those who are dying to communicate their experience of dying is not about finding a suitable opening line; rather, it is about silent presence, which may be the best invitation to speak.

Keywords

Dying, Death, China, Unobtrusiveness, Indirect communication.

Introduction

‘I am sorry. Your idea is difficult’, Y said softly to me. Apparently she felt pity for me—and what she most likely categorised as a strange kind of delusion about the feasibility of my idea. ‘Yes, people get bad diagnoses. But who knows what that means? Even the best doctors can be wrong. So why bother a person by saying “Auntie, you will be dead”?’ I asked whether she thought anybody would want to speak to me. Her response was: ‘It will be difficult.’

When Y and I had this conversation in 2015, I had just arrived in the People’s Republic of China (PRC) to conduct participant observation with people in the Pearl River Delta region who were suffering from terminal illnesses. I wanted to find out what it was like to die in an area where a world-famous fabric industry contributes regularly to foggy weather and ‘foggy’ lung X-rays,¹ and where the effects of aggressive clothing dyes and brutal piecework jeopardise the health of many people on a daily basis.

It is easy for one’s health to decline and to remain that way when working in southern China’s garment industry. Accessing adequate treatment is not easy for current or former garment workers with limited financial resources, especially in the areas where many of those workers live, where healthcare centres are generally overstrained or dysfunctional. Receiving optimal palliative care and pain management in case of incurable illness is even less likely.

Although this was not my first stay in the PRC, I remember being unusually tense right from the beginning—even before meeting any of my potential research participants. The simple reason was that I was supposed to talk to terminally ill people about their own experiences of dying. I seriously doubted whether I was equipped to deal with the pitfalls of talking about dying, especially with Chinese people, who usually grow up with tetraphobia—that is, fear of the number four—because the pronunciation of the number (in Standard Chinese 四, sì) reminds them of the word for death (死, sǐ). This results in practices such as, to take just one widely known example, a conventional avoidance of giving the fourth floor of a building its proper name. Calling death by its name is evidently best avoided.

As it turned out, I was equipped with the conversation skills I would need, but not in the way that I had expected. In the following sections, I would like to offer some impressions of what a terminal diagnosis means in the Pearl River Delta area and

1 See for example Checkoway et al. (2011) for a study that examines how silica and formaldehyde exposure increase the risk of lung cancer for female textile workers in China. See Singh and Chadha (2016) for an overview of relations between particular dyes used in the textile industry and cancer risk in general. Many garment workers I met were well aware that their profession involved risks to their health.

how one of my research participants, Mrs X, taught me a way of talking about dying without actually talking about dying.

Spelling out dying: Non-negotiable inhibitions and questionable diagnoses

At the start of my fieldwork, I managed, with the help of my Chinese colleagues, my friend A and the strength of her *guanxi*,² to settle, at least physically, into my intended research surroundings, which were mostly cancer units of specialised care hospitals and local healthcare centres. However, I did not reach a deep mutual understanding with any terminally ill persons there during my first weeks. This was partly because of the obligation I was under when working in particular settings to gain signatures on informed consent forms. My repeated pleas to potential interlocutors to sign these carefully crafted and legally watertight forms prompted the same reactions that they seem to provoke nearly anywhere in the world: these ranged from mistrust (because an official form was involved) to shame (because of their relative illiteracy) to outright anger. This latter stemmed from devoted relatives who were upset that the form said I was researching those who were dying. ‘How rude are you?’, they asked. ‘What kind of parents taught you to tell an old lady she is basically dead?’ I soon ceased conducting my research in biomedical spaces that required the use of especially long-winded consent forms and instead switched to an interlocutor-centred consent strategy that could involve shorter written agreements, but also allowed for consent to be given orally.

One tricky thing about conducting research on dying in China is the paperwork; another is that it is very, very impolite to say that somebody is dying just because a medical doctor has predicted it. There appear to be strikingly few people in the entire Pearl River Delta region who are definitely dying—just healthy people, slightly sick people, very sick people (who are nevertheless not necessarily incurably so), and people who are actually deceased. The ontological facticity that a terminal diagnosis has in hospital contexts in, say, Finland or the UK—which enables a researcher who wants to talk to people who know and believe that they are terminally ill to include exactly those persons with a terminal diagnosis—simply does not exist for many Chinese people who have had such a diagnosis. A terminal diagnosis in the outskirts of Guangzhou, or in the neighbouring city of Foshan, where many garment factory workers also live, is not primarily a true statement about the inevitable condition of a person; rather, it calls for interpretation and only effects gradual (if any) change as to how a person and her family think about the person’s illness. Even if a person believes that their terminal diagnosis may be

2 *Guanxi* (关系) refers to a complex concept of long-term relationships and social connections. It involves—but is not limited to—a moral obligation to support one another, and mutual trust that the other party will usually provide help and favours when needed.

accurate they are unlikely to show this. In contrast to what I have witnessed in Finland or Germany, in Chinese contexts there is simply no social desirability in what would elsewhere be called realising that one is nearing death. Instead, a person who is too in touch with their approaching demise may be accused by their family of letting themselves down and giving up hope, thereby even causing their own death. For my interlocutors in Guangzhou, therefore, a concretely delivered terminal diagnosis did not equate to the certainty of approaching death.

This belief is compounded by the fact that, as a symptom of a healthcare system in crisis,³ deep mistrust between patients and doctors is not unusual, particularly in the context of public healthcare centres. Obviously, if a patient doesn't trust her doctor, she is unlikely to believe them when they tell her that she is incurably ill. As I learned during the course of my research, a terminal diagnosis initially requires a thorough investigation of one of the following possible factors (in no particular order):

- The doctor is incompetent and may have faked her diploma.
- The doctor is too focused on physical conditions and is unable to see how her patient's health would improve if her son would finally get a less questionable job and/or stop seeing certain undesirable friends.
- The doctor is embarrassed to say she does not have the treatment facilities she needs in order to cure the particular illness.
- The doctor does not want to help because she has no *guanxi* connection with her patient's family.
- The doctor wants a bribe.
- The doctor wants to recommend a more expensive treatment by tricking her patient's relatives into believing that the patient is terminally ill.
- The healthcare centre uses counterfeit medicine that does not really help, so the condition of its patients becomes fatal at the precise moment when they take the drugs that have been given to them.
- The doctor is a very rude person who is unhappy with her private life and so wants to steal the last bit of hope from her patients.

Unfortunately, some of these reasons were not all that unlikely in certain public healthcare centres in Guangzhou in 2015.

Because of all these possible meanings of a terminal diagnosis, most of the clothing manufacturing worker and food stall owner families that I worked with, who were not well-off, were willing to take on substantial debts to try to get their ill

3 See for example Zhou and Gransow (2010) and Zou, Cheng, and Nie (2018) who examine the Chinese healthcare system, particularly how it operates for migrant workers in the Pearl River Delta region, and about the regularity with which deep mistrust exists between patients and doctors.

relatives over to Hong Kong where, as rumour had it, rich people get their mothers cured. If people can't afford that, as is usually the case, they may try to strengthen the doctor's will to cure by means of flattery, bribes, or perhaps even a proper beating-up.⁴

(Not) talking about dying with Mrs X

Some weeks after my slightly discouraging conversation with Y, I met Mrs X and her family. Mrs X was a 58-year-old cancer patient who was being treated at a public healthcare centre ('with specialised medication, not just with the general pills that everybody gets', as she told me). When she and I first spoke, we were waiting in line to enter the crowded entrance hall of said public healthcare centre—she as a patient, me as a researcher. We established a certain bond while witnessing each other's equally fruitless attempts to retain at least a little dignity while sweating profusely and fighting off the local day shift of mosquitoes—a bond which even helped us to overcome the obstacle of informed consent forms. Mrs X understood that I was interested in understanding her world and how she was dealing with being very sick; she liked the general idea of researching 'how people deal with difficulties', as she put it, and decided that she would like to meet me again.⁵

Mrs X's family was not very well off. She had worked in the garment manufacturing business, her son had already pushed the limits of his creditworthiness to pay for the diagnostic efforts of various doctors, and her family was at the point where all the possible reasons for a terminal diagnosis mentioned above had turned out to be false. While everyone, of course, encouraged Mrs X not to let herself down and to keep faith in a cure, I felt that her whole family, including her, were well aware that she would most likely be dead soon. There were sporadic comments about giving away certain objects to female neighbours 'soon'. More than once Mrs X's closest relatives made great efforts to leave the room when the topic of her treatment came up (so that they could cry outside). I even overheard a short discussion between two family members about how nobody was any longer able to afford a 'proper' funeral (involving a burial rather than cremation). Nevertheless, as mentioned above, it would have been the most rude and devastating thing for me to make direct reference during our meetings to the probable fatality of her illness. As my Chinese friend A put it, 'What's the point in talking about that? If you

4 Around the time of the research I describe here violence was a real threat to medical staff. See Rauhala (2014) for a newspaper report from these years and Zhan (2011) and Cooper (2011) for academic reflections on the topic.

5 At a later point, Mrs X confided that she also had hopes that her contact with me would get her better treatment. She thought the healthcare professionals would be impressed that she was important enough to be accompanied by somebody who had come all the way from Europe to meet her.

tell her, you sort of kill her already maybe. It is important to do research on what dying people feel like, but you must not just ask.'

So there I sat on a hot October Monday around midday, intending to ask Mrs X about deeper topics than those we had touched on before in our getting-to-know-each-other chit-chat. I was hoping to finally listen to her perspective on having a terminal illness—and already fearing that I would behave most improperly and cruelly if I addressed directly what I wanted to talk about. Of course, I had written down some seemingly smart ways of opening up the conversation to more personal topics. One idea was to talk about myself or a mutual friend and my—or his—medical diagnoses; another idea was to talk about her doctor's specialisation; yet another approach was to ask her straightforwardly how she was feeling following her latest surgery—the heat meant that the resulting wound was healing only slowly. But for some reason I did not dare attempt any of these conversation starters. They all seemed wrong. I felt as if I had a number of puzzle pieces that would fit perfectly in various contexts, yet none of them was of any use in this particular situation. I usually find it fairly easy to relate to people but, despite all my experience in voluntary terminal care and of accompanying dying persons, I just sat there, with sweaty hands, and could not find the heart to do anything.

Today, I am glad that I didn't. Unintentionally, but fortunately, it was exactly my helpless quietness that encouraged Mrs X to talk about the issue neither she nor I wanted to touch upon directly. When we were just sitting there and saying and doing nothing—simply being next to each other—Mrs X's gaze fell upon a photograph of her grandchild. She started to talk, telling me: 'Z has beautiful black hair there.' I nodded and joined her in looking at the picture. She added: 'I also inherited beautiful black hair from my parents, but after that night before my first breast surgery, it turned white because of the sorrows. Now it is not white anymore; the hair is gone.' I looked at her and nodded again. She continued:

See, you never know if they get you the correct results. I did not want them to take both breasts away. We ladies always want to remain beautiful, don't we? My husband and son talked me into it nevertheless. They said that life is about more than being pretty and that an old woman does not need a breast anymore. I assume they are right.

I instinctively remained silent, captivated by the intensity she put into her words:

Maybe you do not know that. Cancer means—my husband talks about treatments with the doctor to spare me talking about horrible things. And after all, nobody knows the future; even the doctor does not. So it makes no sense to lose your hope and totally depend on what a doctor says—who is only 27 years old maybe. Maybe my health is bad, but there are always things you can

do. You never know what will make you strong—maybe the little things, after they took away parts of your body.

I tilted my head and nodded as she explained: ‘I eat meat soup and eggs when my son brings them, and peaches to cool the wounds from inwards. Young doctors are all about medicine and surgery, but maybe they know too little about what good food and fewer sorrows can do.’ She went on:

My family wants me to be alive; they will never stop pushing me to the doctor. And I feel well with this kind of care; it is kind, it is so expensive, they shouldn’t do that My job is to keep myself happy as long as possible. If it’s hard, that does not matter to me. My main duty is to try to get healthy, for my family, and stay positive.

She paused. ‘Who will look after Z now? She is five.’ I slowly nodded again. Mrs X continued:

We tell her that I have no time to see her now, so she does not cry anymore. She cried when she visited me, all the time; she cries when she sees me sick. So we rather spare her that and tell her something else.

Raising her hand to hide her tears, Mrs X said, ‘I have to exercise my arm now’. I looked at the ground politely, so as not to embarrass her by openly noticing her crying, but I stayed in the room and tried to be by her side in her grief. A little later, her husband entered the room, and we started chatting with him.⁶ However, from that day on, we had new common ground: I was quiet, listening, and at most reactive; she talked whenever she wanted to talk and if she didn’t want to that was fine too.

Mrs X taught me how to research dying in contexts where you simply do not ask about dying: by not talking about it at all. The only thing that worked for me during fieldwork with terminally ill people in Guangzhou was simply not touching upon the topic and instead sitting beside my interlocutors’ beds, not chatting much, not asking much (or anything at all) and trying to focus my attention on them.

During some especially silent fieldwork episodes, I thought how paradoxical it was that the more successful research situations during my stay in the PRC never started with frank initial discussions of my interest in terminally ill persons.⁷ Instead,

6 Mrs X and her husband showed gallantry towards each other in a very particular way. Every day Mr X said, ‘we should get air-con here; it is too hot’, and his wife responded, ‘I would only feel cold with air-con’. Both knew they could not currently afford to install an air-conditioning system. Nonetheless, mentioning that he was willing to invest in one for his wife’s wellbeing was an endearing move on Mr X’s part; blocking this investment in order to prevent her family accumulating even more debt was Mrs X’s way of showing affection for him in return.

7 This condition also points to the fact that research regulations demanding informed consent agreements can complicate or even inhibit fieldwork in some contexts. See for example Dilger (2017) for a more detailed discussion of the topic.

the most fruitful contacts rather evolved based on *guanxi*-related trust. These could be, for example, building on the fact that an interlocutor's relative had been working as a gardener for some time at a university that had hosted a colleague of mine several months ago. In another case, the initial motivation to invite me to meet with them was rooted in the interlocutor's family history. That history reportedly involved a murdered intellectual in the 1960s, which created an instant affection because they regarded me, too, as an intellectual person. In a nutshell, whenever I acknowledged openly the purpose of my research it seemed to put off potential interlocutors and their relatives alike; whenever I relied on approaching people in ways that seemed totally unrelated to my research topic, however, it unlocked doors for me.

As soon as I tuned in to the inevitability of not being able to talk openly about dying in this context, whole new horizons opened up and silence became the respectful and effective conversational strategy that I had so desperately sought. 'A full day of remaining quiet again for me', I noted after a later appointment with another interlocutor; 'maybe these days are all about just being there and doing nothing big and trying to react and to understand'.

Non-intervention, a concept that was recently insightfully addressed by Borgstrom, Cohn and Driessen (2021), is not just a good mode of practice in palliative care. It is also not just the willingness to withdraw from interlocutors if they do not wish to spend their remaining time with researchers. Non-intervention is also one of the most powerful and respectful attitudes to cultivate when one is actually in the field next to a dying person and trying to open up spaces of communication about the nearly unspeakable: the futurelessness that dying implies and what it means for those who feel they may not have much longer to live. Perhaps non-doing and non-speaking—as a form of active receptiveness that prevents us from both being active for activity's sake and from indifference—is exactly the approach that is most appropriate and most promising when it comes to conducting fieldwork with dying persons in China.

Acknowledgements

I would like to express my deep and sincere gratitude to all terminally ill persons who allowed me to be a part of their lives. I would also like to thank the anonymous reviewers for commenting on earlier versions of this contribution. Finally, thank you, Beate Meurer: you taught me a lot about (not) talking to dying persons in general.

About the author

Mira Menzfeld is a cultural anthropologist and a postdoctoral researcher at the Department of Religious Studies, University of Zurich, Switzerland, on the project 'Digital Relationships and Local Religious Communities', part of the Research Priority Program 'Digital Religion(s)'. She is interested in attributions of assumed (non-)veracities to digital rituals; religious knowledge appropriations among transmigrants; Salafism in general; and dying processes in southern China, Finland, Switzerland, and Germany. Her doctoral thesis '*What it Means to Die*' was awarded the Dissertation Prize of the German Anthropological Association in 2019. Recently she edited the special issue 'Empirical Approaches to Salafism in Europe' (2020) of the *Journal of Muslims in Europe* (with Sabine Damir-Geilsdorf).

References

- Borgstrom, Erika, Simon Cohn, and Annelieke Driessen. 2021. "We Come in as 'the Nothing'": Researching Non-Intervention in Palliative Care'. *Medicine Anthropology Theory* 7 (2): 202–13. <https://doi.org/10.17157/mat.7.2.769>.
- Checkoway, H., R. M. Ray, J. I. Lundin, G. Astrakianakis, N. S. Seixas, J. E. Camp, K. J. Wemli et al. 2011. 'Lung Cancer and Occupational Exposures Other than Cotton Dust and Endotoxin among Women Textile Workers in Shanghai, China'. *Occupational and Environmental Medicine* 68 (6): 425–29. <https://doi.org/10.1136/oem.2010.059519>.
- Cooper, Melinda. 2011. 'Experimental Republic: Medical Accidents (Productive and Unproductive) in Postsocialist China'. *East Asian Science, Technology and Society* 5 (3): 313–7. <https://doi.org/10.1215/18752160-1407924>.
- Dilger, Hansjörg. 2017. 'Ethics, Epistemology, and Ethnography: The Need for an Anthropological Debate on Ethical Review Processes in Germany'. *Sociologus* 67(2): 191–208. <http://www.jstor.org/stable/45174690>.
- Rauhala, Emily. 2014. "Why China's Doctors Are Getting Beat Up." *Time*, March 7, 2014. <https://time.com/15185/chinas-doctors-overworked-underpaid-attacked/>.
- Singh, Zorawar, and Pooja Chadha. 2016. 'Textile Industry and Occupational Cancer'. *Journal of Occupational Medicine and Toxicology* 11 (39). <https://doi.org/10.1186/s12995-016-0128-3>.
- Zhan, Mei. 2011. 'Human Oriented? Angels and Monsters in China's Health-Care Reform'. *East Asian Science, Technology and Society* 5 (3): 291–311. <https://doi.org/10.1215/18752160-1347620>.
- Zhou, Daming, and Bettina Gransow, eds. 2010. *Migrants and Health in Urban China*. Berlin: LIT Verlag.

Zou, Xiang, Yu Cheng and Jing-Bao Nie. 2018. 'The Social Practice of Medical Guanxi (Personal Connections) and Patient–Physician Trust in China: an Anthropological and Ethical Study'. *Developing World Bioethics* 18 (1): 45–55. <https://doi.org/10.1111/dewb.12164>.