

# Chinese Sources for AfterWards: From Premodern Poetry, Paintings, and Medical Texts to Modern Novels, Film, and Documentaries

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## Abstract

This paper focuses on Chinese sources suggested for a narrative medicine (NM) program, called AfterWards. Dr Lauren Small established AfterWards in 2014 and has been coordinating it since out of the Pediatrics Department at Johns Hopkins Medicine. In early 2019, she started giving a series of lectures and workshops about AfterWards to Chinese medical educators and clinicians in Beijing and Shanghai. She created an AfterWards *Facilitator's Guide* based on Western-language sources for workshop participants. She also started to organize with Jiang Yuhong (Peking Union Medical College) a workshop for Chinese colleagues to be held at Johns Hopkins Medicine in October 2019. They invited the author to participate. The idea was hatched then to develop Chinese source materials following the AfterWards structure for an updated *Facilitator's Guide* that Dr Small had initially written. A typical one-hour AfterWards session consists of a specific five-part structure: a literary text or artwork, an associated theme, discussion topics, a writing exercise, and shared reflection. While the content of the program always changes from session to session, the basic structure remains the same. This paper summarizes the types of Chinese sources and their related narrative-medicine themes that were originally selected for inclusion in the updated AfterWards *Facilitator's Guide* intended for Chinese colleagues. These sources about coping with sick family members, aging, and illness ranged from the textual (classical Chinese poems on aging and diagnostic forms for training students) and visual (premodern Chinese paintings and murals of medical encounters) to the fictive (novels) and performative (contemporary Asian-American film in English and Chinese-language film and documentaries).

**Keywords:** Documentaries; Films; Murals; Narrative medicine; Novels; Paintings; Poetry

## 1 Introduction

In the summer of 2019, American novelist and essayist Dr. Lauren Small<sup>1</sup> presented me with a major challenge. She wondered if I could help her by including Chinese sources in her *Facilitator's Guide* for running the narrative medicine program called AfterWards<sup>2</sup> that she had established in 2014 at Johns Hopkins Medicine.<sup>3</sup> Small had been an early leader in integrating narrative medicine into the Johns Hopkins hospital system,<sup>4</sup> including writing up work with colleagues in palliative care.<sup>5</sup> She was thinking about ways to expand her reach to China, where she had been working with Jiang Yuhong

(蒋育红) of the Peking Union Medical College. Jiang Yuhong was the Chinese colleague we both knew and who introduced us to each other.

Dr. Small suggested that I develop six new sessions based on Chinese sources to replace six of 12 of her original sessions. Excited about this opportunity, I decided to feature the widest range possible of Chinese primary sources that had medical themes from premodern times to the contemporary period. Instead of being exhaustive about possible primary sources in Chinese culture, I selected a few exemplary types of materials. Although these selected sources have obvious medical humanities interest, the narrative medicine use may not be immediately evident. Thinking with them in mind through the AfterWards structure, however, demonstrated how rich resources for deeper reflection these Chinese primary sources could become (Table 1). Although the full range of methods in narrative medicine has been introduced to Chinese audiences<sup>6</sup> and even a broad-ranging narrative-medicine reader of Western-language materials has been published in Chinese,<sup>7</sup> to date no work has introduced Chinese sources that could be productively used for narrative medicine.

Furthermore, although availability in English would not be necessary in native-Chinese-speaking contexts, all Chinese sources chosen for the AfterWards *Facilitator's Guide* had to be visual materials that did not require

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**Table 1** Selected topics, themes, and writing prompts for AfterWards sessions using Chinese sources

	Topic	Theme	Writing prompt
1	Poems by Han Yu (韩愈 768–824), Bai Juyi (白居易 772–846), and Zhu Dunru (朱敦儒 1080–1175)	On Aging	Write about an observation or craft a poem about aging in yourself, someone else, or a patient.
2	“Moxibustion,” <i>Jiu Ai Tu</i> (灸艾图), attributed to Li Tang (李唐 1049–after 1130)	When Healing Hurts	Write about your experience with the tension between treatment pain and healing goals.
3	“A Form to Use for Diagnosing, for my Disciples,” in <i>Yi Tang San Ji</i> (怡堂散记) by Xu Yuhe (许豫和 1785)	How to Make a Diagnosis	Write about when you had difficulty making a diagnosis, or being diagnosed, and how the problem was resolved.
4	“The Farewell” (2019), Asian-American film written and directed by Lulu Walsh	Patient’s Right to Know	Write about any conflicts you’ve experienced over releasing medical information to someone.
5	“Full Circle,” ( <i>Fei Yue Lao Ren Yuan</i> 飞越老人院, 2012), film written and directed by Zhang Yang (张杨)	Patient Autonomy in Advanced Years of Life	Write about a time you, or someone you know, had to decide to move someone into a senior-living facility.
6	<i>Dream of Ding Village</i> ( <i>Ding Zhuang Meng</i> 丁庄梦, 2006) by Yan Lianke (阎连科), novel that inspired Ministry of Health’s public-health campaign to counter HIV/AIDS stigma: “Love for Life,” ( <i>Zui Ai</i> 最爱, 2011), a film directed by Gu Changwei (顾长卫), filmed with “Together,” ( <i>Zai Yi Qi</i> 在一起, 2011), a documentary on people living with HIV/AIDS by Zhao Liang (赵亮)	Dealing with Stigma	Write about your experience having to deal with disease stigma—for example, a patient, friend, family member, yourself, or witnessed someone else experience.

translation, texts that had English translations, or performative works with English subtitles. This choice was made because Chinese cultural resources could then be used for AfterWards and other narrative medicine programs conducted in English. The selected sources were intended as a first step to introduce basic types of possible premodern textual and visual sources as well as contemporary Asian-American film and Chinese novels, films, and documentaries that could be used for narrative medicine ends. A book, published recently in Chinese on doctors in western novels, films, and dramas,<sup>8</sup> would be a good model for a book on the same theme but about medical issues and practitioners featured in contemporary Chinese fictional and performative works.

Although this article focuses on how these Chinese sources could be used within the AfterWards five-part structure, they are presented here as examples of the rich Chinese cultural archive of primary sources that could be productively utilized in already existing narrative medicine programs in medical schools and hospitals across Chinese mainland and throughout the sinophonic sphere.

The premodern sources included classical Chinese poetry on themes of aging such as losing one’s teeth and eyesight from the 9th to 12th centuries, a 12th-century Song painting of a healer giving painful moxibustion treatment, and an 18th-century essay on how to make a diagnosis that a physician wrote to help his disciples.

The modern sources focused on Chinese novels, films, and documentaries as cultural resources. An Asian-American film, “The Farewell,” dealt with cross-cultural differences about an elderly patient’s right to know about a cancer diagnosis. A Chinese comedy “Full Circle” similarly dealt with generational conflicts over issues of autonomy for the elderly through a story of a theater group who would like to perform in a competition outside of their senior residence. Finally, the Chinese Ministry of Health sponsored a film “To Live”

(based on the novel *Dream of Ding Village*) and a documentary “Together” about people living with HIV/AIDS to address the serious problem of social stigma toward people living with HIV/AIDS in Chinese mainland.

Each of the following seven subsections of this article provides a six-part lesson plan for how these sources could be used in an AfterWards session: 1. the type of Chinese primary source, its main topic, and three possible outcomes, 2. introduction to the topic, 3. background of the primary source, 4. possible discussion topics, 5. writing prompts, and 6. questions for reflection. These lesson plans are intended to facilitate anyone who would like to run a narrative-medicine program similar to Dr Small’s AfterWards to be able to introduce the material to the audience, set up topics for discussion, suggest a writing prompt, and provide further questions for reflection to help conclude the session.

The goals of this article are therefore twofold. First, to make it more feasible for medical educators and clinicians in China to start a narrative-medicine program modeled on AfterWards that uses Chinese cultural resources. Second, to introduce broad categories of textual, visual, and performative materials already existing in Chinese culture that people could consider integrating into their existing narrative-medicine programs in China.

## 2 On aging

This session focuses on the rich possibilities of using Chinese classical poetry for cultivating narrative competence through close reading and reflective writing,<sup>9</sup> the first two of what Rita Charon called “tools of narrative medicine.”<sup>10</sup> China has a rich archive of illness narratives that could be used for this purpose from newly excavated texts starting in the 4th-century BCE<sup>11</sup> to early medieval Chinese anecdotal literature.<sup>12</sup> Chinese poetry has been

selected for this session because, in addition to volumes of collections of Chinese poetry being readily available in the original Chinese language, there are also many edited volumes of English translations of Chinese poetry,<sup>13</sup> including several that focus on women poets.<sup>14–16</sup> The trick is to select from these extensive collections on Chinese poetry, health-related poems. This session focuses on three well-known poets—Han Yu (韩愈 768–824), Bai Juyi (白居易 772–846),<sup>17</sup> and Zhu Dunru (朱敦儒 1080–1175)<sup>18</sup>—all of whom wrote moving poems about aging, a topic of concern not only for the elderly themselves but also for their family members and caregivers. Han Yu wrote in about 803 a poem on “Losing Teeth” (*Luo Chi* 落齿), Bai Juyi crafted in 814 a poem titled “My Eyes Grow Dim” (*Yan An* 眼暗), and Zhu Dunru penned a poem in 1175 he titled “Nirvana, the fourth one” (*Nian Nu Jiao Qi Si* 念奴娇其四), but which Nathan Sivin summarized as “On Ripe Old Age.”<sup>19</sup>

## 2.1 Outcomes

- Reflecting on the myriad processes and attitudes toward aging
- Considering the timelessness of sentiment toward aging
- Appreciating culturally specific ways of expressing sentiment through poetry
- Imagining the aging patient’s perspective *via* a poem

## 2.2 Introduction

The theme of perceiving one’s own aging, or witnessing the aging of others, is certainly universal. Life stages are an integral part of human life. And yet our attitudes toward the aging of ourselves and others not only change as we grow older but also change how we think about people we witness aging before our eyes. Geriatricians deal with such issues as part of their daily work but, for physicians in other medical disciplines, such changes may be less obvious or harder to perceive. These poems offer an opportunity to explore how some Chinese poets have addressed aging. Through their own personal experiences expressed in verse, one can examine one’s observations and attitudes about this later stage of life through close readings of these poems and personal reflection through writing in prose or verse in response to them.

## 2.3 Background

Nathan Sivin (1931–2022), formerly Professor Emeritus of Chinese Science and Medicine at the University of Pennsylvania, translated these three poems to honor the 80th birthday in 2011 of Theodore Friend (1931–2020), an American scholar of Islam, especially in Indonesia and the Philippines, as well as the former President of Swarthmore College and of the Eisenhower Foundation. The editors of the journal *Asian Medicine: Tradition and Modernity* requested to publish Sivin’s translations as part of an effort to make translations of medically

relevant texts in East Asian languages more easily accessible to a broader readership.

The three poems selected here are by masters in Chinese poetry. Han Yu was a famous statesman as well as prolific literary figure of the Tang dynasty. In this poem on his decaying teeth, his style is more innovatively conversational and informal than that of his predecessors. Dentistry was not well developed in China, or elsewhere for that matter, before the 20th century. Most people just rinsed their mouths and brushed their teeth with some kind of tool. In China, they usually did this with a willow twig. Should their teeth hurt or become decayed, they had to have them pulled out.

Second, Bai Juyi was an official and recognized as one of the greatest Tang poets. In poor health, he wrote several poems about losing his eyesight. This one captures the comfort he found in the Buddhist concept of ending suffering through enlightenment in the face of useless medicines.

Finally, Zhu Dunru was better known as a hermit poet and painter before, at 55 years old, he was given an official title and summoned to court. The reason for this was mainly based on his fame as a poet. Crafted sometime near the end of his nearly 100 years of life, we find by contrast with the two other poems featured here, no complaint on aging but rather a clarion call for living in the moment.

## 2.4 Discussion topics

- How does Han Yu express his changing attitude toward losing his teeth?
- What does Han Yu mean by his reference to “Master Zhuang” and “what’s useless at least survives?”
- Do the metaphors “lamp,” “mirror,” and “dust” that Bai Juyi uses for losing sight signify something larger?
- What metaphors does Zhu Dunru use and for what broader point about life?

## 2.5 Writing exercise

Write about a time when you recognized you were aging, or you suddenly recognized aging in one of your patients, or you notice such changes in someone you know well. Did you find your attitude toward yourself, your patient, or that person changed as well, or not? If you are so inclined, craft a short poem about one of your observations on aging.

## 2.6 Reflection

- Do you think these poets use verse effectively? How and why?
- What differences in attitude can you find among these three poems?
- Do any of these poems resonate particularly with you?
- If you were to craft a comparable poem, what would you focus on? Why?



**Figure 1** “Moxibustion Illustration,” (灸艾图 c. 1130–1150), attributed to Li Tang (李唐 c. 1050–after 1130), in Courtesy of Palace Museum in Taipei (source from: <https://theme.npm.edu.tw/exh102/form10204/ch/ch02.html>).

### 3 When healing hurts

This session focuses on traditional Chinese paintings with a medical theme that could be used for further developing close-looking skills (parallel to close reading), in this case of artworks, in narrative-medicine programs. Rita Charon’s emphasis on healthcare professionals developing their sense of “self” and “presence” in clinical encounters can be effectively addressed as well *via* depictions of medical encounters. In fact, there are three extant Chinese paintings depicting various types of medical activities and encounters that date to the Song period (960–1279).<sup>20</sup> The oldest example is one mural that was found with two other murals in a tomb (c. 1070) discovered in March 2009 in Hancheng, Shaanxi. This tomb mural depicts people making medicinals in a drug-making workshop while the pharmacist (possibly tomb occupant) oversees production.<sup>21</sup> It is worth noting here that a collection of mural paintings of Buddhist and Daoist rituals from the Ming dynasty<sup>22</sup> also contains many medically relevant scenes of suffering, such as one of a miscarriage and dying mother (Note 1).<sup>23</sup>

The second Song example is the famous scroll “Qingming on the River” (*Qing Ming Shang He Tu* 清明上河图), attributed to court painter Zhang Zeduan (1085–1145) who likely completed it under the court patronage of Emperor Huizong (r. 1101–1125).<sup>24</sup> Amid the bustling commercial street scenes on the scroll, two pharmacies are portrayed. As the scroll unfolds from right to left, the first pharmacy depicted is open to the public street and flanked by medical advertisements. A physician studies an infant held by one woman while another woman looks over her shoulder.

The third Song example is also a Song court painting (Fig. 1). But in contrast to the urban setting of the pharmacies in “Qingming on the River,” it depicts a medical encounter in the countryside. Titled simply “Illustration of Moxibustion,” (*Jiu Ai Tu* 灸艾图 c. 1130–1150) and attributed to court painter Li Tang (李唐 c. 1050–after 1130), this painting strikingly depicts a medical encounter during which the patient is clearly experiencing pain. This session focuses on the third painting and its unusual portrayal of when the healing treatment involves some necessary pain.

#### 3.1 Outcomes

- Reflecting on occasions when pain is necessary for healing
- Exploring healing settings outside of modern-day clinics and hospitals
- Considering the role of family and friends in the healing process

#### 3.2 Introduction

Sometimes treatments necessary for healing are, in fact, initially painful. Patients expect their healthcare providers to know when pain is necessary for the healing process and how to manage it for therapeutic ends. Clinicians have a great deal of responsibility on their shoulders to understand their patients’ pain experience. They also must manage the patient’s pain that comes with treatment. This painting arguably captures that moment when the treatment intended to heal also involves first inflicting pain. This is a moment most clinicians have experienced and so have had to manage it emotionally as well as medically. But it is not

only a one-on-one clinical encounter that physicians need to concern themselves with when inflicting pain to affect a cure. This painting portrays the physician concentrated on applying the moxibustion on the patient's back while two women support him through the pain. A frightened child peeps out from behind the elder woman's back. The physician's assistant, however, stands apart from the rest apparently amused by the scene unfolding in front of him.

### 3.3 Background

The Chinese landscape painter, Li Tang (c. 1050–1130), was a native of Heyang, Henan province and first served under Emperor Huizong (r. 1100–1126) during the Song dynasty in Bianjing (汴京, now Kaifeng 开封). In Bianjing, he earned the highest rank in the Song imperial court's Painting Academy. The northeastern Jurchen Jin regime (1115–1234), however, invaded Song in 1126, forcing the abdication of Emperor Huizong. When in 1127, the Jin successfully conquered much of the northern territories of the Song and captured Huizong with many members of his court, the remaining court and other refugees fled south to Qiantang (钱塘, now Hangzhou 杭州). There they enthroned one of Huizong's sons as Emperor Gaozong (r. 1127–1129). Few of Li Tang's paintings survive and so most paintings attributed to him, such as "Moxibustion," remain questionable. Nonetheless, he was one of the most influential Song landscape artists and his general style can be seen in the broader rural setting of this painting.<sup>25</sup>

### 3.4 Discussion topics

- Why might an imperial Song court painter famous for lush landscapes and complex court scenes depict a common rural scene for a medical encounter?
- How does this court painter depict the rural itinerant doctor of his time?
- Is the medical encounter depicted favorably, critically, or ambivalently?
- How does he portray the patient, family members, and other people in the scene?
- What kind of doctor–patient relationship is portrayed here? Equal or hierarchical? Sympathetic or conflicted? Familiar or estranged?

### 3.5 Writing exercise

Write about a time you had to inflict pain to heal, or when you experienced or witnessed an occasion when the pain of treatment was necessary for the healing process. Or perhaps write on when unnecessary pain was the result of an otherwise well-intentioned treatment.

### 3.6 Reflection

- How does this painting depict the tension between treatment pain and healing goals?
- Who is involved and what roles is each person playing in this treatment situation?

- Did anything strike you as unexpected in this painting? Why?
- Is the treatment setting completely foreign or do you see possible similarities with some situations today?

## 4 On making a diagnosis

The history of medical case records in China has been well studied in terms of its origins in premodern China,<sup>26</sup> transformations in modern China,<sup>27</sup> and as a way of thinking that transcends the medical field.<sup>28</sup> From Chinese antiquity<sup>29</sup> to the Song<sup>30</sup> and into the Republican period,<sup>31</sup> cases are particularly rich resources for narrative medicine. This session focuses on a rare but important type of essay in traditional Chinese medical texts that is important for making a case record, namely the diagnostic form. Some physicians created model diagnostic forms for their medical students to learn how to take a patient history. This medical genre is thus particularly useful to develop what Rita Charon calls the "three movements"—attention, representation, and affiliation.<sup>32</sup> This is what Guo Liping (郭莉萍) has translated into the "three elements" (*Yao Su* 要素).<sup>33</sup> The "three movements" ("elements") mean to pay attention to patient's narrative, represent what they say about their condition and situation, and establish an affiliation with them. One can still learn from how past Chinese physicians systematized for their students—what to ask, observe, and record—with the goal of ensuring their patients' trust.

This session uses specifically "A Form to Use for Diagnosing, for my Disciples" that the late 18th-century Chinese physician, Xu Yuhe (许豫和) included in his *Yi Tang San Ji* (《怡堂散记》 *Random Notes from the Hall of Contentment*) published in 1785.<sup>34</sup> As other articles in this special issue on Chinese sources for narrative medicine have shown, Chinese medical texts are particularly rich repositories for narrative medicine. This session focuses on what one physician considered to be most important for taking a patient's history and how he conveyed that to his students. Although what is considered important in a patient's clinical history changes over time and differs across healing modalities, taking a patient's history, and training medical students to do the same effectively, remain central concerns in medical practice and education.

### 4.1 Outcomes

- Reflecting on what is essential (and no longer essential) for taking a patient's history
- Understanding how the narrative frame informs clinical observations
- Considering what narrative forms best ensure patient trust and communication
- Examining how clinical reasoning requires some kind of narrative form

### 4.2 Introduction

Every clinician makes decisions about how to evaluate a patient, what signs to consider and what to ignore, whether

the symptoms present something minor or more serious. Then the clinician needs to determine what kind of therapy should be administered and if pharmaceutical, what dosage is appropriate, and after administered, whether the therapeutic intervention was efficacious. All clinical reasoning requires narrative form. This AfterWards session focuses on what are the multiple roles—cognitive, clinical, pedagogic, and social—of “a form to use for diagnosing” and how that form may differ historically, culturally, and even from one’s own personal or clinical experience.

### 4.3 Background

The 18th-century Chinese physician Xu Yuhe was an average literate doctor of his time who chose to record his clinical experience in “random notes,” a narrative genre typical for recording personal observations more broadly. The standard form for diagnosis that he published for his disciples is neither the first nor the only example in Chinese medical history. It is a good example of how physicians then evaluated their patients, planned drug therapy, emphasized evaluating efficacy, and valued recording clinical observations and thoughts “clearly and in detail.” Over 2000 years of the history of the forms and contents of the related genre of medical case records is also particularly well documented in Chinese medical history.

### 4.4 Discussion topics

- Although published over 300 years ago, are there similarities with modern-day diagnostic forms and methods?
- Do any of the listed criteria for evaluation suggest older forms of perception that may still be clinically useful today?
- Why is recording clearly and in detail important for this physician?
- Do you recognize any therapeutic methods in those this physician listed?
- How do these “random notes” compare to the electronic medical record of today?

### 4.5 Writing exercise

Write about a time when you had difficulty making a diagnosis, or you experienced problems being diagnosed, and if the problem was resolved, explain how it was. Or, if you are so inspired, write out a list of what you think should be essential criteria for taking a patient’s history.

### 4.6 Reflection

- Do you agree with this author that clear and detailed records are related to ensuring patient trust?
- What modern narrative forms are used as “models for the medical profession?”
- Are enumerated lists of possible therapies comparable to this physician’s “seven formulas” and “ten prescriptions” still used today?

- Does this historic diagnostic form provide anything useful for clinicians to pay better attention, accurately represent, and build affiliation with patients today?

## 5 Patients’ right to know

This session generally introduces the potential power of contemporary films dealing with illness to illustrate the four trust relationships related to affiliation in narrative medicine. These four trust relationships are conventionally those that physicians have with their patients, with themselves, with colleagues, and with society. Films that take as their subject the experience of illness and its effects on the sick individual and their wider social network of friends and family are especially useful cultural lenses for illustrating trust relationships. But such films can also push viewers to consider trust relationships beyond those centered on the physician to include also the trust relationships between the patient, their family members, and friends.

This session thus focuses on one Asian-American film titled “The Farewell” (别告诉她, 2019) that takes on the issue of a patient’s right to know about their disease diagnosis (Fig. 2).

When the Chinese matriarch of a family is diagnosed with terminal cancer, her sister and other members of her family in China think it is best for her not to know so as to reduce her fear in her final months. But her Chinese-American granddaughter questions this familial decision. The grandmother’s physician did not inform her as his patient either but rather lets her family decide what to do with the medical information. Trust relationships are indeed central to this story—as everyone believes they are acting in the best interests of the patient—but not in the ideal way summarized in narrative medicine. “The Farewell” adeptly presents cultural differences about individual patient autonomy, familial expectations, and good intentions through the conflicting opinions about whether the patient’s right to know is in the patient’s best interest.

### 5.1 Outcomes

- Exploring patient notification of diagnoses at the end of life
- Considering the role of families in determining the release of medical information
- Reflecting on cultural differences and patient autonomy

### 5.2 Introduction

Patient autonomy can be one of the most difficult questions to navigate in delivering medical care. In some cultures, such as in the United States, it has become expected, and even required, to inform patients of their diagnoses and engage them actively in treatment decisions. Patients control who has access to their medical information, including family members. Other cultures,



**Figure 2** Asian-American film, “The Farewell” (别告诉她, 2019), by Director Lulu Wang (王子逸) (source from: [https://en.wikipedia.org/wiki/The\\_Farewell\\_\(2019\\_film\)#/media/File:The\\_Farewell\\_poster.jpg](https://en.wikipedia.org/wiki/The_Farewell_(2019_film)#/media/File:The_Farewell_poster.jpg)).

however, may take a different view, and prefer to withhold information from patients either because of family wishes or because of a general belief that it is better for the patient to do so. This session of *AfterWards* explores some of the complex issues regarding patient autonomy at the end of life.

### 5.3 Background

“The Farewell” is a film written and directed by Wang Lulu that was released in 2019.<sup>35</sup> It tells the story of a Chinese family whose grandmother has received a diagnosis of terminal lung cancer. The family decides to hide the diagnosis from the patient, believing this to be in her best interest. To give family members the chance to say goodbye to their beloved grandmother, they stage a

wedding to which everyone is invited. One branch of the family has emigrated to the United States, and when the patient’s granddaughter Billi comes for the “wedding,” she challenges whether her grandmother should remain ignorant of her medical condition.<sup>36</sup>

“The Farewell” is a full-length feature film that runs for 98 minutes. Given enough time, groups may choose to view the entire film. Otherwise, they may focus on a few key scenes, such as the moments where Billi discusses the family’s choice to withhold the diagnosis from her grandmother: first, when she’s with her parents and learns of her grandmother’s illness; then when she’s in the spa getting “cupping”; and finally when she is in the hospital and learns from her grandmother’s sister that the grandmother had also not informed her husband that he was dying until the very end.

### 5.4 Discussion topics

- How is Billi depicted in the movie as navigating two cultural worlds? How does she express her mixed Chinese-American identity?
- What kind of relationship does Billi have with her grandmother? How does she react when she learns that her grandmother is dying?
- What does Billi think when she learns that her family plans to withhold her grandmother’s diagnosis from her?
- What kind of arguments does the family present in order to justify their withholding of medical information?
- What kind of cultural differences play into the differences between Billi’s view of her grandmother’s right to know her diagnosis and her family’s?

### 5.5 Writing exercise

Write about a time you, or someone you know, had to make a decision about whether or not to release medical information to a family member or patient. Or imagine how you would react should you discover that your family or partner had kept your medical information from you in an act of love and looking out for your best interest.

### 5.6 Reflection

- How is patient autonomy generally viewed in your culture?
- What are the benefits of withholding medical information? What are the risks?
- How can clinicians navigate difficult situations when family members or patients don’t agree on the release of medical information?

## 6 Patients’ autonomy in advanced years

This session introduces the potential of films to be useful for teaching yet another dimension of the value of narrative medicine, namely, to be moved to action through narrative competence. The first sentence of the book Rita Charon co-edited, *The Principles and Practice of*

*Narrative Medicine*, states this goal clearly: “Narrative medicine began as a rigorous intellectual and clinical discipline to fortify healthcare with the capacity to skillfully receive the accounts persons give of themselves—to recognize, absorb, interpret, and be moved to action by the stories of others.”<sup>37</sup> Many films that focus on illness, or even just a sense of ill-being, provide the patient’s perspective on their condition and how their stories can inspire action in others.

Although Chinese film has rarely focused on medical practitioners or institutions or even individual experiences of illness, there are nonetheless noteworthy examples that deal with medical themes such as suffering, disability, aging, and dying. Although the bilingual Chinese film website called YiMovi was formulated within the framework of Chinese medical humanities, it also has potential to be a good online resource for films that could be used for teaching narrative competence.<sup>38</sup>

A few of the films featured on YiMovi deal with illness experience and patient narratives—autism, cancer, and living with HIV/AIDS (featured in the next subsection)—but most of them fall under a broader umbrella of complex emotional-physical states of “ill-being.”<sup>39</sup> Many of the YiMovi films address illness experiences within this broader ill-being thematic. This is certainly the case with the film “Flying Over the Senior-Living Home” (*Fei Yuan Lao Ren Yuan* 飞越老人院, 2012), known in English as “Full Circle,” which was written and directed by Zhang Yang (张杨) (Fig. 3).

The elderly Chinese residents of a senior-living home demonstrate their agency in many ways in this film from finding meaningful activities individually and collectively to self-care and caring for each other. But their agency has limitations when it comes to their family members’ expectations for their safety and the care facilities concerns about liability. Ultimately, the skeptical, concerned, and restrictive family members and representatives of the institution come to understand the elders’ positions, perspectives, and aspirations.

## 6.1 Outcomes

- Exploring patient autonomy and agency in advanced years of life
- Underscoring the value of mental stimulation, creativity, and useful occupations for the elderly
- Considering how high levels of elderly wellbeing can co-exist with serious, even terminal, illness
- Reflecting on cultural differences in family expectations related to the care of and autonomy of elderly patients

## 6.2 Introduction

The autonomy of elderly patients and family members is an especially difficult issue to navigate in delivering compassionate medical care. In some cultures, such as in China, families are expected to take care of their elders as long as possible within their own homes or in the homes

of their children. Specialized communities for the elderly such as senior apartment buildings, retirement homes, nursing homes, and assisted living facilities are not as widespread and common as they are in the United States. The Chinese value of filial piety remains strong for parents who expect their children to take care of them in advanced age within their own homes. However, this is quickly changing in China and many elderly people find themselves with no living relations or with children for various reasons unable to look after them. This session of *AfterWards* explores some of the current issues regarding autonomy of the elderly and who and what institutions should be responsible for their care and well-being.

## 6.3 Background

“Full Circle” is a film by writer-director Zhang Yang released in 2012. Director Zhang has been successful in finding ways to tell stories about contemporary Chinese family life that appeal to the mainstream Chinese public and also gets past government censors. “Full Circle,” like his earlier “Spicy Love Soup” (1997), “Shower” (1999), “Quitting” (2001), “Sunflower” (2005), and “Getting Home” (2008), fits well into the genre of Chinese films that focus on family home life as a lens on broader conflicts between traditional mores and modern social transformations.

In “Full Circle,” the setting is a retirement home where the family conflicts are over autonomy as well as the sentiment between elderly parents and their children and grandchildren. As a means for one of the members to reach out to his child living in Japan, some of the elderly form an acting troupe to enter a Japanese TV talent competition in Tianjin. But when their family members and the nursing home staff refuse to allow them to leave the premises, they break out and take off in a run-down bus to pursue their acting dreams. The Administrative Head and Chief Nurse, however, are hot on their heels in pursuit.<sup>40</sup>

## 6.4 Discussion topics

- What are some of the challenges facing care of the elderly and dying?
- Do you see anything depicted in this film specific to the challenges China is facing?
- How are the elderly depicted in the movie? How do they find agency in their lives?
- How are generational conflicts related to traditional Chinese family values depicted? Are they resolved or not?
- How do conflicts between tradition and modernity play out within this example of a “family-separation” genre situated within a nursing home?

## 6.5 Writing exercise

Write about a time you, or someone you know, had to make a decision about moving a family member or a patient into senior apartments, a nursing home, or an





**Figure 3.** Film, “Full Circle” (飞越老人院, 2012), by Zhang Yang (张杨) (source from: <https://www.yimovi.com/movies/full-circle>).

assisted living facility. Or instead, imagine yourself living in a home for seniors comparable to what was depicted in the film and write what you imagine would be most important for you to have to be happy living there.

## 6.6 Reflection

- How is autonomy of seniors and the elderly generally viewed in your culture?
- What are the benefits and pitfalls of moving elderly patients into assisted living care facilities?
- What role should clinicians play when family members or patients are debating a move into a senior apartment building, nursing home, or the like?
- How can agency and quality of life be improved for elders with diminished capacities?

## 7 Dealing with stigma

This session focuses on an extraordinary example of a Chinese novel about the HIV/AIDS tainted blood scandal in 1990s China that inspired a top-level government-coordinated public-health campaign against disease stigma (Fig. 4). This campaign resulted in both a film based on the novel and a documentary about people living with HIV/AIDS in China. This multimedia collaboration of film director, documentary maker, and public-health officials was intended to reduce discrimination and stigma against HIV-positive people by strengthening the public’s understanding of AIDS through entertaining and informative cultural forms.<sup>41</sup>

Although considerably simplifying the original story, both film and documentary did unprecedented cultural work to reduce the stigma of living with HIV/AIDS in China. Physicians are notably not present in any of these cultural responses to the HIV/AIDS epidemic in China; rather the personal stories of the fictive characters in the novel and film and of actual people living with HIV/AIDS in the documentary are central, making the novel, film, and documentary excellent opportunities for people to empathize with the accounts people narrate about their own illness experiences living with HIV/AIDS.

### 7.1 Outcomes

- Considering how some diseases have more social stigma than other ones
- Evaluating how different cultures respond to disease stigma
- Understanding how the Chinese Ministry of Health responded to the social problem of HIV/AIDS stigma

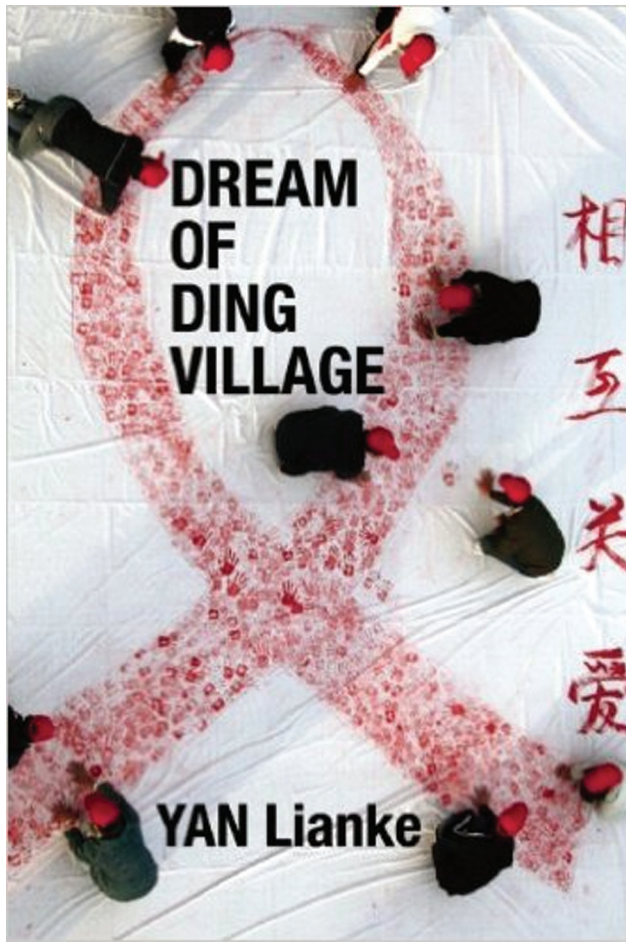
### 7.2 Introduction

Why is it that some diseases come with more social stigma than others? Susan Sontag in *Illness as Metaphor* famously wrote about the social stigma of being diagnosed with cancer.<sup>42</sup> Sexually transmitted diseases, such as syphilis, and more recently HIV/AIDS, are particularly laden with social stigma and so also discrimination. Just being sick has potential for stigmatization. This AfterWards session provides examples of how different cultural forms may be used to counter particularly hurtful disease stigma, giving hope for better communities and lives for those who are ill.

### 7.3 Background

Released in 2011, *Love for Life* (Zui Ai 最爱) was the first feature-length movie to address the HIV/AIDS epidemic in Chinese popular culture (Fig. 5).<sup>43</sup> The director Gu Changwei (顾长卫) based the film on novelist Yan Lianke’s (阎连科) considerably more nuanced and critical work of fiction titled *Dream of Ding Village* (*Ding Zhuang Meng* 《丁庄梦》). Many other equally effective and moving Chinese novels dealing with illness narratives and disease stigma could be used to develop narrative competency.<sup>44</sup> The film’s sympathetic portrayal of HIV+ characters through a romantic love story, which is also at the heart of the novel, attempts to counter the real-life stigmatization and discrimination against people living with HIV/AIDS in China.

As part of this HIV/AIDS public health education campaign sponsored by the Ministry of Health, Zhao Liang (赵亮 d. 1971), one of China’s best-known independent documentary filmmakers, was invited to make the documentary. The resulting *Together* (*Zai Yi Qi* 在一起) combined footage of the making of *Love for Life* and interviews with people living with HIV/AIDS in China (Fig. 6).<sup>45</sup> These people included the film’s HIV+ and



**Figure 4** Novel, *Dream of Ding Village* (丁庄梦, 2006; English translation 2011), by Yan Lianke (阎连科) (source from: <https://www.amazon.com/Dream-Ding-Village-Yan-Lianke/dp/0802145728>).

non-HIV+ actors and extras with at-home interviews and online exchanges that Zhao Liang arranged through online social networks with people living with HIV/AIDS in China. Clips of “Love for Life” and “Together” are available on the bilingual website devoted to making available resources related to Chinese film and cross-cultural medical humanities.

### 7.4 Discussion topics

- Why is HIV/AIDS called “the fever” in “Love for Life” (as in the novel)?
- What is the underlying moral message behind “Love for Life” and “Together?”
- Are you aware of any other films and documentaries the Chinese Ministry of Health has sponsored as part of other public health campaigns?
- Could the approach manifested in this film and documentary have other applications for other public health problems and diseases?

### 7.5 Writing exercise

Write about your experience having to deal with disease stigma associated with one of your patients, or someone



**Figure 5** Film, *Love for Life* (最爱, 2011), director Gu Changwei (顾长卫) (source from: [https://en.wikipedia.org/wiki/Love\\_for\\_Life#/media/File:Love\\_for\\_Life.jpg](https://en.wikipedia.org/wiki/Love_for_Life#/media/File:Love_for_Life.jpg)).

you know, or that you’ve witnessed socially or experienced personally. Another option is to write about a particularly good cultural response to disease stigma—a film, novel, documentary, poster, essay, etc—that moved you and explain why.

### 7.6 Reflection

- What other novels, films, and documentaries have been used for public health ends?
- How is the Chinese experience with the stigma of HIV/AIDS similar with or different from the US or other countries?
- What other diseases carry comparable social stigma?
- What other cultural forms could be mobilized to reduce disease stigma?

## 8 Conclusion

This essay has introduced six major types of Chinese sources that were proposed for the *Facilitator’s Guide for AfterWards*, a successful narrative-medicine program



**Figure 6** Documentary, *Together* (在一起, 2010), director Zhao Liang (赵亮) (source from: [https://en.wikipedia.org/wiki/Together\\_\(2010\\_film\)#/media/File:Together\\_\(2010\\_film\)\\_poster.jpg](https://en.wikipedia.org/wiki/Together_(2010_film)#/media/File:Together_(2010_film)_poster.jpg)).

that Dr Lauren Small has been operating at Johns Hopkins University since 2014. The lesson plans developed for each type of source are intended to facilitate adopting the AfterWards model of a narrative-medicine program in China by using Chinese-language material. Many types of Chinese sources deal with medical themes from the textual (poetry, anecdotes, medical texts, novels, etc) and visual (paintings, scrolls, murals) to the performative (film and documentaries).

All of these Chinese resources have great potential for teaching narrative competency in existing narrative medicine programs in Chinese medical schools and hospitals. This essay's goal, however, was not merely to introduce Chinese sources for narrative medicine in China but ultimately to inspire further work by Chinese scholars based on the rich Chinese cultural archive on illness narratives and other medical themes from the earliest examples in antiquity to contemporary literature, film, documentaries, and artworks.

## Notes

1: All three pictures are discussed at length in article cited in [20]. One mural painting is on the book's cover cited in [23].

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## Ethnic approval

This article does not contain any studies with human or animal subjects performed by the author.

## Author contributions

Marta Hanson did the research and wrote the paper.

## Conflicts of interest

The author was Guest Editor of this special issue.

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