



Life after cancer and the communist order: A case study on grassroots patient organization in China

Ying Chen^{a,*}, Cheng Pang Lee^b

^a Department of Sociology, National University of Singapore, AS1#03-06, 11 Arts Link, 117570, Singapore

^b Department of Applied Social Science, The Hong Kong Polytechnic University, HJ402, Hung Hom, Kowloon, Hong Kong

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ABSTRACT

Patient-led organizations have mushroomed in China over the past three decades, but they have not received enough academic attention. This paper aims to explore the survival logic of patient-led organizations and forge a critical analysis of the imbrications of patient life and state power in a non-neoliberal context of contemporary China. Based on seven months of ethnographic fieldwork and 41 interviews, we examine the case of the Shanghai Cancer Recovery Club (SCRC) as an example of a highly mobilized cancer survivorship that evolved from a group practicing Qigong. Unlike its counterparts in the liberal societies, SCRC has a completely different historical process of group formation. Decades ago, Chinese cancer patients believed that pre-modern “Qi” could control cancer, so they gathered to practice Qigong. To unify and better promote Qigong among cancer patients, they later formed a more organized Qigong milieu. After the Qigong fever, Qigong groups formed by cancer patients gradually evolved and registered as an official cancer social organization. Based on the idea of Chinese values of collective living and the revolutionary spirit of communism, SCRC promoted very innovative “group cancer-fighting method” (e.g., grassroots based, large-membership, and motivating slogans). Through these, they have succeeded in building a citywide network that reaches down to the street level. As the oldest and largest patient-led organization in contemporary China, SCRC serves as the Shanghai model that has influenced hundreds of similar patient-led organizations in other cities. We further argue that SCRC has played three roles in the current medical system: as a welfare arm of the government, as a collaborator with medical institutions, and as a mediator between the public and patients.

1. Introduction

When a staff member of the SCRC¹ was asked about how they were fighting cancer, he replied: ‘The Western model of conquering disease highly relies on medical science and technology, but we Chinese patients succeed because of our collective organic social interactions.’² Founded in 1989, SCRC is the oldest and largest social organization established by cancer patients in Shanghai, or even among all the disease groups in China. All members, including staff and volunteers, have been diagnosed with cancer at one time or another, many of them at an advanced stage. Some have just become ill, some have been ill for three or five years, some have been ill for more than ten years, and some have been ill for more than twenty years.

SCRC evolves from a group that practices Qigong and highly

embraces Chinese communist ideology. Several characteristics of SCRC differentiate it from the patient groups known in the Western societies where patient and patient-led organizations are more focused on providing professional counselling and “active” in promoting their rights and resistance (Barbot 2006; Landzelius, 2006). First, SCRC is a large and membership-based organization, with 15,313 members in Shanghai alone. The organization has a well-trained and hierarchical structure, with layers of leadership, orders, and disciplines. All members have extensive or short period experience of eating, living, and practicing Qigong together. Second, the organization emphasizes the importance of cultural beliefs in curing cancer. Dozens of slogans such as “Ask not what the society can give you, but what I can do for the society.”; “Uncontented with the world and fight for your life, seek nothing but to survive.”; or “My today is your tomorrow; your today is my yesterday.” are

* Corresponding author.

E-mail addresses: chen.ying@u.nus.edu (Y. Chen), Cpalee@polyu.edu.hk (C.P. Lee).

¹ SCRC is an abbreviation for Shanghai Cancer Recovery Club (*aizheng kangfu julebu*).

² Interview with a staff member of SCRC, September 2019.

created. SCRC has advocated that “five years from now, no one will be left behind”. They claim that the five-year survival rate for cancer in SCRC is over 80%, compared to about 55% in Shanghai city and the national average of about 40%.³

SCRC has long been recognized by professionals and local governments for its achievements in creative initiatives of ‘Group Cancer-fighting Method’ (*qunti kangai*). Over the past three decades, similar cancer clubs have flourished in almost all cities in China, influenced by the SCRC model. Despite the significant role cancer clubs play in the current medical and health system, their importance has not been fully explored by scholars. In this paper, our aim is not to examine whether individual patients’ health conditions have improved as a result of group practice. Rather, we are more interested in knowing the origins, nature, and impact of SCRC as a representative of similar cancer clubs in contemporary China. Our research questions include: What was the historical formation process of SCRC as a grassroots patient-led organization? How does it survive for decades in an authoritarian state? How does it collaborate with the state-run health care system?

Through examining this representative patient-led organization, it enables us to further explore the issue of Chinese medical reform from the often-ignored patients’ perspective. The medical and health reform is one of the most important public policy issues for the Chinese government. Since the 1980s, the marketization of the medical system has led to what scholars call the ‘Great Reversal’.⁴ To address the problems of increasing medical costs and difficult access to health care (*kanbing nan kanbing gui*), the Chinese government has initiated several waves of medical reforms in the past, but the early reforms did not really change the deteriorating situation. A comprehensive reform effort was implemented in 2009 and its results are still being evaluated.⁵ The existing literature tends to address the reform issues at the policy level⁶ in terms of finance,⁷ public health and central-local relationships.⁸ These studies point to the crucial role of government in policy reform and how the complex structure of governments has impeded the medical reform.⁹ There are also recent studies that aim to understand the situation of doctors, given the prevalence of verbal and physical abuse against them.¹⁰ However, the experiences of Chinese patients and Chinese patient-led organizations are rarely studied in the existing literature of Chinese medical reform. At the same time, scholars studying the history of philanthropy and the development of civil society in China have found that medicine has been one of the main focuses of foreign NGOs, and many of these earlier medically-oriented foreign NGOs remain influential to this day (e.g., The Rockefeller Foundation).¹¹

Similar to other countries, Chinese patients form different types of organizations to facilitate their interests and strive for their rights. Those who form formal or informal organizations to fight for their rights and compensation from medical malpractices could be seen as a type of “rightful resistance”.¹² Chinese patients are found to hold a view that formal medical institutes care more about revenues rather than taking care of patients.¹³ On the other hand, those patient organizations that often serve as the intermediate role between the formal medical institutes

and individual patients are out of scholarly scrutiny, but they are an important component of the Chinese civil society and welfare infrastructure.¹⁴ We do not aim to examine all types of patient organizations in this paper, but only examine those in the form of patient clubs, a mutual-help organization. In our analysis, we will use SCRC as a case to show how this type of organizations teaches their members to fight against cancer, and their important position between the formal medical institutes and individual patients. By studying these, we also aim to understand the development of Chinese public sphere and civil society with Chinese characteristics in the context of medicine.

Our paper is organized in the following manner. First, we discuss the literature related to cancer survivors and patient-led organizations in the context of the Chinese medical reform. Second, we briefly introduce our methodology and outline the founding history of SCRC. Third, to decode the uniqueness of group cancer-fighting method, we further explain the relationship between SCRC and Chinese communist ideology. We view SCRC as a Chinese communist-styled mass mobilization of cancer survivors. Lastly, we examine the impact of SCRC. Or more precisely, how SCRC positions itself within formal institutions. We conclude our paper with a short summary of our findings and the implications of our research.

2. Patient-led organizations and China's medical reform

The phenomenon of patient advocacy and activism has been an important topic in the study of medical and health system transformation and has been studied more extensively in other countries, but has not been studied in the Chinese context.¹⁵ Much of the existing literature on patient-led organizations, based on US and European cases, presents patients’ counter-voices about their experience of illness (Kleinman, 1980), rather than “disease” as defined by professionals. Patients’ scepticism of professional expertise has led them to form patient-led organizations to challenge the “power inherent in expertise and the profound dilemmas facing social movements seeking to ‘democratize’ science and technology” (Epstein, 1996, p. 330). Along this line, patients grouped by diseases reconstitute themselves into different “interest group” such as campaign for patient rights (Fleischer & Zames, 2011), combat stigma (Clair, Daniel, & Lamont, 2016), medical ethics (Brown & Zavestoski, 2004, p. 682), feminist health movements (Joffe et al., 2004), and environmental movements (Brown, 2007).

However, SCRC and other similar Chinese cancer clubs cannot be understood in this light. Its development has to be contextualized along with China’s medical reform and the problems it poses. Since the 1980s, the Chinese medical system has undergone a dramatic shift from a socialist system into a hybrid system. Between 1949 and 1978, the socialist medical system emphasized public ownership and collective welfare. Essential health care services were provided almost free of charge in both urban and rural areas; peasants with little education worked as part time health care workers, commonly known as barefoot doctors, and were able to offer medical services after three to six months of basic medical training.¹⁶ This centrally planned medical system was gradually replaced by a hybrid system based on market logic.¹⁷ Initially, this new system was intended to address issues of efficiency, bureaucracy, and quality of health care services by introducing market competition, but it has created more problems than expected.¹⁸

The market-oriented medical reform raised mainly four major issues: under-funding and under-provision of public health and preventive health services, high health care costs, unaffordable access to health care,

³ Shanghai Municipal Health and Wellness Commission. 2021. “Shanghai Municipal Health and Wellness Commission Five-year cancer survival rate in Shanghai 55% continues to rise for more than a decade”. April 15. <http://wsjkw.sh.gov.cn/xwfb/20210415/3bae5eb22d61411c82a6bf9d38eed431.html>. Accessed June 22, 2021.

⁴ Chen, 2001.

⁵ Yip & Hsiao, 2009; Yip et al., 2012; Qian, 2014.

⁶ Bloom, 2011.

⁷ Hsiao, 2007.

⁸ Ma et al., 2008.

⁹ Qian, 2017; Yao, 2016; Qian, He, & Yin, 2019.

¹⁰ Yao, Zhao, & Lu, 2017.

¹¹ Ryan et al., 2014.

¹² O’Brien & Li, 2006; Yao, Zhao, & Lu, 2017; Zhang & Cai, 2019.

¹³ Yan, 2018.

¹⁴ Teets, 2009; Howell, 2015, 2019.

¹⁵ McCoy et al., 2017; Rickard et al., 2019.

¹⁶ Wang, 1975.

¹⁷ Chen, 2001.

¹⁸ Hsiao, 1995; Blumenthal & Hsiao, 2005; Fang, Chen, and Rizzo 2009; Hsiao, 2007; Hsiao, 2014; Gu & Zhang, 2006; Ma et al., 2008; Watts, 2006.

and medical impoverishment.¹⁹ These problems have been attributed to the market-oriented medical reform and China's unique political system.²⁰ It is argued that the Chinese political system encourages party leaders, health bureaucrats, sub-national governments, and public health care units to tend to shirk their responsibilities in providing affordable, accessible, and equitable health care services.²¹ Scholars argued that transformation of the health governance structure is increasing the power of health care providers while reducing the influence of government and patients.²²

Under the old socialist system, patients' right to access medical services was guaranteed and tied to his workplace. However, the new medical system has put patients in precarious situations because of the increasing health care cost and the difficulty of accessing medical care. It has been found that Chinese patients perceive the formal medical institutes as being more concerned with revenues than with taking care of patients.²³ Patients' frustration and dissatisfaction have led to the deterioration of the "doctor-patient relationship" and the prevalence of "medical violence" (*yinao*) phenomenon.²⁴ However, Chinese patients and their collective will have received little attention in the current literature even though patients are the primary victims of the medical reform. Patient-led organizations, which often serve as intermediaries between formal medical institutes and individual patients, are usually out of scholarly scrutiny, but they are a critical component of the Chinese civil society and welfare infrastructure.²⁵

In this paper, we aim to examine SCRC as both the collective voice of the individual patients and a patient-led organization in contemporary China. Readers may argue that patient and patient-led organizations are two different study objects, yet the argument does not apply to SCRC. In contrast to those right-based advocacy groups, SCRC remains individual-based with a collective goal of every individual patient's cancer recovery rather than patient rights as a public issue. Also, the patient advocacy groups in the liberal societies are mostly small-sized, with no more than 35 members (McCoy et al., 2017), while SCRC represents a large membership.²⁶ According to the Shanghai Municipal Health Planning Commission, there are currently 490,000 cancer survivors in Shanghai.²⁷ Out of these, SCRC has 15,315 members and that shows how representative SCRC is. In our analysis, we will use the case of SCRC to show how this type of organizations help their members to better fight against cancer, and their crucial role between the formal medical institutes and individual patients.

3. Methods

Our research is based on a seven-month long ethnographic work, as part of the dissertation fieldwork. The fieldwork was first conducted in

Shanghai, Beijing, and Zhenjiang between July 2018 and September 2018 and then mainly in Shanghai from September 2019 to January 2020. We chose Shanghai as the main case for two reasons: (1) SCRC is the first officially registered grassroots cancer organization in China; (2) SCRC serves as the Shanghai model has influenced and helped with the establishment of 105 similar cancer organizations nationwide in China. The first author, also the ethnographer, participated in SCRC as a full-time volunteer and was given access to the club's administrative work, daily group activities, and large-scale events. In addition to the volunteer work and participatory observations, the ethnographer also visited hospitals, Qigong practice sites, and teaching locations to interact with the cancer patients. The conversations mainly focused on the topics of daily life of cancer patients or survivors, such as their hospital encounters, Qigong practices, and their life experiences etc.

A cancer patient's connections, relationships or networks to doctors and hospitals enable one to have better access to medical resources and reflects his position in the Chinese system. A rather interesting side note on building such relationship was frequently experienced by the ethnographer. Initially, when the SCRC members learnt that the ethnographer is a doctoral student, they would deliberately approach her and add her as a contact on WeChat and the like. However, when they found out that the ethnographer is not a medical student, they became lukewarm. What most cancer patients like to discuss at the dinner table is, for example, "My cousin's son is a medical student and is now interning at which hospital".²⁸ Or someone will happily share, "I went for a drink today and there was a doctor at the next table, so I rushed up to toast him and asked which hospital he was at".²⁹ Doctors, as well as medical students, are the scarcest human resource for information and networking resources in SCRC. This is in contrast to the scepticism of patient-led organizations in the US and European countries towards doctors and scientific professionals.

The first author also conducted 41 interviews with 27 women and 14 men to know more about the experiences of these individual leaders, staff, and patient members in SCRC. The interviewees range in age from 50 to 70 and all are Shanghai residents (native Shanghaiese or Shanghai identity card holders). They are either retired or had to quit their jobs because of their sickness. These interviewees come from relatively diverse occupation and socio-economic background; they include mostly factory workers, occasionally school teachers, owners of small companies. SCRC has 18 staff, and about 200 patient leaders (*gugan*) divided into three different levels: city office, district office, and community. All staff and patient leaders are cancer survivors and volunteers. The analysis of the interviews was conducted using the thematic analysis method. In addition to the fieldwork and interviews, we also examined newspaper archives and government documents in this study. The newspaper archives are collected from reports in Shanghai "Liberation Daily" (*jiefang ribao*) where SCRC was mentioned, while government documents are those official responses to SCRC recommendations on health care policy.

4. A brief background of Shanghai Cancer Recovery Club

SCRC was formed in 1989 in Shanghai by cancer survivors, Yuan

¹⁹ Hsiao, 2007, 242.

²⁰ Duckett, 2011.

²¹ Huang, 2009, p. 6.

²² Ramesh, Wu, & He, 2014, 740.

²³ Yan, 2018.

²⁴ Lancet, 2010, 2014; Lee, 2019; Tam, 2012; Yan, 2018.

²⁵ Howell, 2019.

²⁶ Here we use the size of the patient group to show the difference between SCRC and its fellow patient groups in liberal societies. According to Mancur Olson and his article of "The Logic of Collective Action". Olson argues size matters to social groups. Small groups generally function better than big groups in providing better public goods because big groups have to solve the free rider problem. SCRC and many similar patient-led organizations in other cities, post a theoretical puzzle, which is, why as non-profit social organizations, they managed to sustain such a large membership since its very beginning?

²⁷ Shanghai Municipal Health and Wellness Commission. 2021. "Shanghai Municipal Health and Wellness Commission Five-year cancer survival rate in Shanghai 55% continues to rise for more than a decade". April 15. <http://wsjkw.sh.gov.cn/xwfb/20210415/3bae5eb22d61411c82a6bf9d38eed431.html>.

Accessed June 22, 2021.

²⁸ Quote from fieldnote on July 5, 2018.

²⁹ Quote from fieldnote on November 18, 2019.

Zhengping³⁰ and his small peer group practicing *Guolin Qigong*³¹. The founding of SCRC was reported by the “Liberation Daily” (*jiefang ribao*) in the same year (see Table 1). The report applauded the mission of SCRC and described it as the first “patient self-organized clubs” (*bingyou julebu*). However, SCRC maintained its informal mutual-help organizational status until 1993, when Yuan registered it as a social organization with the Shanghai Ministry of Civil Affairs.

SCRC's founding and its success in becoming the largest patient-led organization are closely linked to its founder, Yuan who was born in 1950 to a working-class family in Shanghai. After completing high school, he worked as a worker for a stevedoring company and became a union staff later. In 1989, he became the party secretary of the publicity department of the Union of Shipping Shanghai until his official retirement in 2003. Like every other patient group in the world, SCRC provides information, emotional support, and educational programs for new cancer patients. Yuan's initial motivation for establishing SCRC was to provide a support group for cancer patients to share their personal experiences and information, and to give emotional support to each another. These functions remain till today.

In SCRC, patients have many ways to exchange information and advice. These methods range from offline groups divided by different cancer types to hundreds of online groups. Some SCRC volunteers provide their personal phone numbers to patients they meet in hospitals in case they need help. Wang Guowei, an experienced volunteer and a cancer survivor in SCRC regularly went to different hospitals and gave his phone number to cancer patients he met. He spent more than 10 hours answering phone calls from strangers.³² Internet-based patients groups

have the advantages of having both privacy and intimacy compared to face-to-face groups. Despite of their old age, they continuously update their technology to create websites and utilize increasingly sophisticated online social and telecommunication platforms such as Weibo, WeChat, and QQ to promote their group cancer-fighting philosophy. Now they have even developed their first mobile app named ‘Home of Hope and Love’ (*xiai jiayuan*). The software application provides information about activities and offers different knowledge from professional experts and patient experts. SCRC even publishes an official magazine called ‘Recovery News’, four volumes in a year, in print and online versions. All these platforms help new patients to get the latest information on cancer treatment, to find good hospitals and to choose among them, to select a new primary care doctor, and to decide collectively which treatment option is best for them.

Emotional support also matters. Many members shared with the ethnographer that before joining SCRC, they mostly stayed at home and rarely interacted with people. They felt that others would not understand them, even their loved ones. But at SCRC, people can empathize with each other because they have all experienced the same difficulties caused by the disease.³³ Emotional support helps suffering patients break free from tension and negativity, thereby gaining the ability to express their fear, anxieties and grief, and develop hope for recovery. Joining a cancer club like SCRC is seen as a way to transform fear into a task-centred approach—a desire to actively and rationally fight the disease. The founder Yuan, shared, “Through people's positive interaction, emotional signals are passed from one person to another; people adopt belief from other stronger spirits to live a happier life. People usually come feeling desperate but leave seeing glimmers of hope”.³⁴ As a result, this creates a strong feeling of community and familiarity.

SCRC also has educational programs to help patients deal with their disease. Any new patient who joins the club is placed in separate small groups focused on a specific kind of cancer, depending on the type and stage of cancer they have been diagnosed with. In these small groups, doctors not stating the side effects of treatments or surgeries and doctors prescribing drugs indiscriminately to make money are hot topics in meetings and group chats. Other activities, from daily tips to learning a new hobby, also provide an outlet. New patients are reminded right from the outset that, in addition to medical treatment, a positive mindset and a healthy lifestyle in the name of ‘spirit of living’ are crucial to their recovery. They are also encouraged to turn to a mix of Chinese and Western medicine, especially the potential role of non-drug interventions such as Qigong, Buddhist meditation and Traditional Chinese Medicine, in order to heal and enhance their health during cancer recovery. They are offered “music therapy” (*Xiyu*), which is extracted from Peking opera music; this music is claimed to have therapeutic effects.³⁵ The combination of different treatment strategies is further reflected in a higher philosophical discussion about health, medicine, and the differences between Western and Chinese views of body. In their view, Western medicine, as represented by the US model, relies on medical science and technology to conquer disease. In contrast, Chinese patients succeed because of their collectivity.

Table 1
Major events in SCRC (1989–2019).

Date	Events
7 November 1989	The article of ‘We have a Club for cancer patients in Shanghai’ got published in <i>Liberation Daily</i> , which was the one of the most official newspaper in Shanghai. The article made SCRC widely known by the general society.
23 January 1990	Zhu Rongji, then mayor of Shanghai city, called twice to express his concern for cancer patients in SCRC.
20 December 1991	SCRC launched a campaign to select 100 cancer-fighting stars from its members.
5 March 1993	SCRC was approved by the Shanghai Civil Affairs Bureau as a registered non-governmental organization.
November 8 1993	Shanghai Cancer Recovery School was established and proved by the district level Education Bureau in Shanghai. The first group of 50 students joined the school.
2 May 1997	The rehabilitation centre for people to speak again after laryngeal surgery was firstly established. Since then, 13 rehabilitation and guidance centres have been established for liver, lung, stomach and breast cancers.
7 November 1989	SCRC celebrated its thirtieth anniversary.

³⁰ The president of SCRC, Yuan Zhengping's life story is so rare that it is impossible to keep his identity anonymous, and therefore I use his real name in this research project.

³¹ Guo Lin Qigong originated from a painter named Guo Lin. She was born into a martial arts family. At the age of six, she learnt Qigong and the Five Auras of Huatuo under her grandfather, a Taoist priest at the Medical Age Temple. In 1949, Guo Lin was diagnosed with uterine cancer and treated with a total hysterectomy. After ten years of Qigong study and practice, she finally created a self-contained system of “New Guo Lin Qigong”. In 1971, Guo Lin began teaching Qigong to the community, and in the 1980s, Guo Lin brought about the third wave of Qigong in China.

³² Xu, Chi. 2016. “Wang Guowei: rang bingren ganshou manman de xingfugan” (Wang Guowei, he serves cancer patients for their happiness). *Xinmin News*, 10 December. <http://shanghai.xinmin.cn/xmsq/2016/12/10/30671787.html>. Accessed May 14, 2019.

5. Fighting cancer in the communist order

As a cancer organization, SCRC advocates a unique way to fighting cancer that goes beyond the sharing of information typical of the western patient self-help organization. We identify two unique characteristics of SCRC: (1) It is a patient-led organization that evolved from a Qigong practicing group, and later embraced a group cancer-fighting method developed from the Chinese communist style of mass mobilization. The

³³ Interview with a SCRC member, Shanghai, October 2, 2019.

³⁴ Interview with Founder and President of SCRC, Yuan Zhengping, Shanghai, July 3, 2018.

³⁵ Interview with a patient leader, Shanghai, July 2, 2018.

group cancer-fighting method emphasizes the Chinese values of collective living and the revolutionary spirit of communism to win the war against cancer. (2) The second characteristic serves to elucidate the first, namely SCRC's ideological alignment with the state. Although a registered social organization, SCRC retains its early identity – its affinity with the state ideology – as a Qigong group. Not only in its ideology, but also in its organizational structure and practices, SCRC highly imitates the Chinese Communist Party. Through all of this, SCRC establishes relationships with local governments, which facilitate the SCRC's legitimacy under harsh social governance (Spires, 2011).

5.1. Group cancer-fighting method

For SCRC members, cancer recovery is more about social and psychological factors than about those medical indicators. According to the president of SCRC Yuan, SCRC's training programs and courses are designed to transform a person spiritually, preparing him for his first five years of survival and even for the longer journey to a possible full recovery in the future. As a cancer survivor as well as a patient leader who has personally lived through all the patients' experiences, Yuan is not only educating but indeed inspiring. He continues to share his story and experiences to encourage fellow cancer patients.

‘That year, in 1981, on the seventh day of my marriage, I was told I got this dreadful cancer and only had a year to live. I hadn't really come to terms with the shocking news, but I had already moved from my red bridal bedroom to the white hospital room...After completing treatment a few years later, I returned to my workplace. I felt completely out of place and everything had changed. My peer colleagues, even the younger ones, blatantly beat me in many ways. Every time they sat down to talk about their jobs and careers, I felt lost and miserable. Sometimes I think that if I didn't have this disease, I would have most likely gone on to higher and better jobs. Not only me, many fellow cancer patients are facing discrimination at their workplace...Therefore I decided to start an organization for ourselves. In 1989, SCRC was registered. So far, I have been living with this cancer for 38 years and our club is about to turn 30 years old...’³⁶

To many members, Yuan is not only spiritually inspiring, but he is always a capable and intelligent leader. A small anecdote illustrates this latter point well. In the autumn of 1989, Yuan was working for the ‘Shanghai Federation of Trade Unions’ (*shanghai zong gonghui*). Once, when he sent a union manuscript to the *Liberation Daily*, the editors asked him for any topic that would warm the heart and resonate with readers. He brought up the SCRC story and all the editors agreed with the idea. That is how the article of ‘Shanghai has a cancer patients club in Shanghai’ was published in *Liberation Daily*.³⁷ Yuan was responsible for several innovations in the collective approach to fighting cancer. He proposed the campaign to select Cancer-fighting Stars from among the members of the SCRC. The Cancer-fighting Stars are chosen annually by a selection committee formed by the SCRC to highlight members who have experienced extreme and severe disease conditions, but have successfully survived for at least five years after diagnosis. The first Cancer-fighting Stars Contest, ‘A Selection of One Hundred Cancer-fighting Stars’, was held on December 20, 1991.

When asked about the essence of ‘group cancer-fighting’ methodology, Yuan said: ‘Many of the patients here end up spending all their money and died. This ‘group cancer-fighting’ does not really address the roots of any problems. It merely makes people feel happy for a while, and that makes sense to us. If you can't get out of the darkness, you light a candle. The analogous act of lighting a candle is a job for the government or society to do, while cancer patients focus on their recoveries from the illnesses. Ironically, it is done by those of us with cancer ourselves. The

problem is that if we don't do it, no one else will. So, we must do everything on our own, cautiously...’³⁸ There are some historical threads behind Yuan's slightly critical discourse.

5.2. Affinity with the state ideology

SCRC is a registered social organization. It is not a GONGO because its leaders and staff are all volunteers and do not receive direct government support. However, its organizational structure and organizational culture are highly like those of the party state. Fig. 1 shows the comprehensive organizational structure of the SCRC which resembles the *tiao-kuai* system in which a complex network of relationships connects the centre and peripheral, top and bottom of the cellular organization. Under the board of directors and supervisors, there are nine functional departments (e.g., the Recovery School). Each department has its own three levels of sub-units from the district level to the community level. According to its 2020 annual work report, SCRC claims to have 15,315 members, 35 board members, 7 supervisors, and 18 staff in the secretariat office.³⁹ The district offices are registered with the district government as independent social organization, as the law prohibits the establishment of branches in different districts. All membership fees, RMB 50 per member, are paid directly to the SCRC city office.

The SCRC congress is composed of representatives of different district associations. All members of the SCRC are managed according to their area of residence. The head office in the city is at the top of the hierarchy. The city office has 18 volunteers. Under the city office, there are 20 district offices, 182 street-level branch offices, and 300 community level branch offices. Thus, SCRC has incredibly strict and hierarchical vertical lines of authority from the central office at the city level to the divisional offices located in different administrative areas to the community developmental stations. In this system, members are categorized into ordinary members, volunteers, core leading volunteers, station masters, district leaders, and municipal leaders. To become a volunteer, ordinary members must submit an application form that is approved by an upper-level committee. Upon approval, they will receive training and may have the opportunity to be promoted as core leading volunteers (*gugan*) in their respective districts. The same principle applies to any other level of authority. Any volunteer who has accumulated his/her experiences and efforts over the years will earn the opportunity to be promoted to the central authority at the city level. Promotions at all levels are made through a systematic selection process.

The close relationship between SCRC and the party state dates back decades, when SCRC was a Qigong group. As a Qigong group, SCRC grew out of the common organizational integration of Qigong practitioners, mainly cancer patients, their understanding of pre-modern *Qi* and the utopia goal for having all cancer patients to join them in the practice of Guo Lin New Qigong, which is meant to heal through pure mental effort. During that time, all Qigong groups, except Falun gong, were aligned with the state ideology (Palmer, 2003; Chan, 2004). Later, SCRC's founding was also closely associated with a group of retired communist cadres and led by a charismatic leader, Yuan. In addition to using communist-styled mobilization strategies in his day-to-day work, Yuan put great efforts into maintaining good relations with local governments. As party secretary of the publicity department of a large local union, Yuan was familiar with those who worked in the official media. This relationship enabled Yuan to get the *Liberation Daily* to write a positive story on the establishment of SCRC entitled ‘Shanghai has a cancer patients club’ (*shanghai youjia aizhenghuanzhe julebu*).

Why did the *Liberation Daily* do this? Was it simply because of Yuan's personal connections, or because of the importance of SCRC? According to Yuan, the government was concerned about people's low morale after

³⁶ Interview, Yuan Zhengping.

³⁷ Interview, Yuan Zhengping.

³⁸ Interview, Yuan Zhengping.

³⁹ Source: Shanghai Shehuizuzhi gonggong fuwu pingtai. <http://shzz.mzj.sh.gov.cn/node1/zhuizhan/index.html>. Accessed Mar 20, 2020.

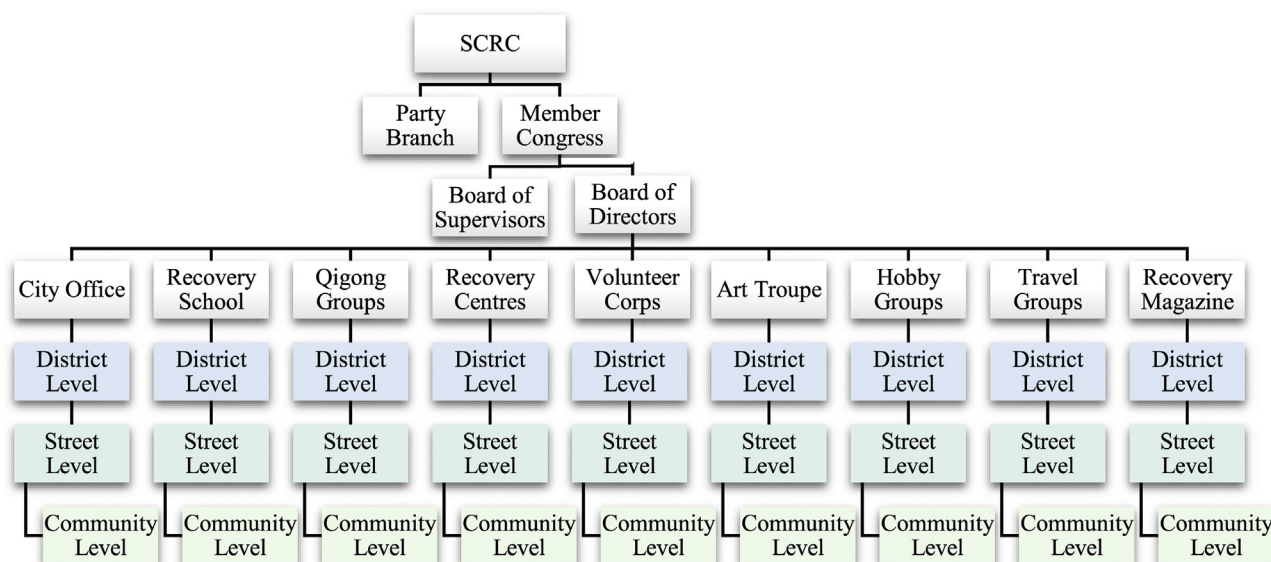


Fig. 1. The organizational structure of SCRC

the 1989 Tiananmen Square Protest and wanted the story to warm ordinary hearts.⁴⁰ After the first report, *Liberation Daily* again reported on SCRC, this time with a story titled “True warmth exists in our society” (*renjian ziyou zhenqing zai*) that appeared on the front-page cover on December 5, 1989. Based on our interviews with Yuan and others, the second report attracted national attention. On the first report written, the journalist of *Liberation Daily* reflected on the social fever it generated, as cancer patients and their families, and even ordinary citizens across the country continued to write to the newspaper offices to praise the strong spirit of the SCRC as a pioneering self-help patient group in China.⁴¹ This even led Zhu Rongji, then mayor of Shanghai city, to call SCRC twice in 1990 to discuss his willingness to provide governmental support.

The similarities between SCRC and the Chinese communist party can be explained in part by the role that retired communist cadres played in the founding of SCRC and other similar organizations. In 1982, the party-state announced a white paper on “The Central Committee of the Communist Party of China made a Decision on Cadres’ Retirement Rules” (*zhonggong zhongyang guanyu jianli laoganbu tuixiu zhidu de jue ding*). It states that the central government hopes that retired cadres will contribute to the cause of the Party, the country and the future of the people. Old retired cadres are encouraged to set up any relevant social groups or organizations to devote their remaining energy, as they still have political influences.⁴² Although the document does not directly target patient-led organization, it gives the local government a source of legitimacy to support clubs that are led by communist cadres. For example, the local government forced the unregistered Zhengzhou Cancer Club, which had been operating for twenty years since 1992, to merge into the newly formed Henan Old Cadres Cancer Association (*henan sheng laoganbu guanxin aizheng huanzhe xiehui*).⁴³

The annual work report and the tightening of government policies toward interest groups also made SCRC’s actions more careful and

prudent manner. On March 13, 1997, SCRC chose and had to choose to become a ‘Spiritual Civilization Construction Group’ (*jingshen wenming jianshe qunti*) and to adhere to governmental agenda of socialist spiritual civilization. This deprived them of any possibility of fighting for patients’ rights like patient advocacy groups in liberal societies, and instead became entirely a network of therapeutic social organizations. While political conservatism has allowed SCRC to survive and thrive in a hostile environment, it has also limited its social action to a certain extent. For example, even as one of the oldest civil society organizations, they have not dared to explicitly express their dissatisfaction with government provided medicine as a public good, instead using high levels of performance to gain legitimacy for their discourse. For instance, their performance is reflected in all their activities, and they will show their most ramshackle life experiences to the official media. All of this is very different from patient groups in liberal societies, which are smaller and more private. In those cases, the more severe the disease is, the more private the social organization.

A portrait of Xi Jinping has been displayed in the guest hall of SCRC. The picture was taken in 2007 when Xi was the party secretary of Shanghai municipality. He interviewed the award-winning individuals and teams at the Volunteer Excellence Award ceremony, of which SCRC was one team. On the same wall as Xi’s portrait hangs a quote: “Ask not what society can give you, but what I can do for society,” written on a red board. Once a staff shared that phrases like these are necessary for them to pass government examination such as the annual “Spiritual Check-up”. In the office guest hall, SCRC has a list of accolades under its name: 5A Grade Social Organization, Outstanding Civil Society, Shanghai Charity Star, Shanghai Outstanding Volunteer Groups, Best Civilized Unit in Shanghai for eleven consecutive years. As the only cancer patient-led organization in Shanghai, SCRC enjoys a monopoly status and its sub-units regularly receive different forms of government supports, including grants, and government contracts. For example, SCRC’s premises have been donated by the Shanghai Charity Foundation for nearly two decades. With this, SCRC can sustain and even grow to a larger scale. We have described in details in previous sections how SCRC looks after the welfare of its members. However, its welfare function goes beyond providing medical and recovery consultancy.

These state-run ideological and cultural activities do not translate into a statement that the SCRC is the propaganda arm of the Chinese Communist Party. We interpret the imitation of organizational structures and the use of propaganda from the Chinese Communist Party for the

⁴⁰ Interview, Yuan Zhengping.

⁴¹ Gao, 1991.

⁴² “Zhonggong zhongyang guanyu jianli laoganbu tuixiu zhidu de jue ding” (The Central Committee of the Communist Party of China Made a Decision on Cadres, <http://cpc.people.com.cn/GB/64162/71380/71387/71591/4854975.html>. Accessed May 16, 2019.

⁴³ Ge Jiqian, “Laoganbu guanxin aizheng huanzhe xiehui tuidong le qunti kangai de fazhan” (The retired cadres have promoted the development of Chinese cancer clubs), *Annual Meeting of Nationwide Cancer Clubs*, 1 April 2010.

legitimate purposes under the regime, and it has a long history since the Qigong fever time. The interpretation is based on the concept of 'institutional isomorphism.' According to Paul DiMaggio and Walter Powell, an organization's process or structure may imitate another organization in a given context (DiMaggio & Powell, 1983). The organ donation campaign clearly illustrates the working relationship with the Chinese government. Over the past few years, the local government in Shanghai has been formulating public policies to promote organ donation. They have established a Promotion Charter committee and launched campaigns aimed at raising societal awareness and acceptance of organ donation. SCRC was invited to be guest performers at these events. Volunteers, especially those with liver cancer, dressed in yellow elementary school uniforms (signifying new-born) and red scarves (signifying Young Pioneers of CCP), sang a song called "Saying Thanks with a Grateful Heart". The performance had won support of many people to achieve the goal of the organ donation campaign. This type of strategy promotes good relations with the government. Apparently, the singing, dancing, provision of public goods, and the propaganda uses pleased the government. However, in this case, the use of propaganda was more as a communication channel to make their voices heard to the government. In China, the "Say my words in your language" strategy has become increasingly important for civic organizations, echoing Czech political activist Václav Havel's view of "Power of the Powerless" (Havel, 2009).

6. SCRC's role in the Chinese welfare infrastructure

As a registered social organization focused on cancer patients, SCRC occupies an interesting position in the current Chinese welfare infrastructure. Unlike those patient advocacy civil society organizations common in Western societies, SCRC does not engage in policy advocacy activities or directly promote patients' rights. We do find members and staff complaining about problems of the current medical system, high costs, and government inaction. However, these complaints will not escalate into collective action that aimed at changing the status quo. Instead, staff and leaders will help members to find a practical solution within the system. SCRC can provide practical solutions based on individual needs, largely because of its high level of connection to local government, formal medical institutes, pharmaceutical companies, and the media. We report three roles for the SCRC in the current Chinese welfare infrastructure. (1). As a welfare arm of the local government; (2). As a collaborator with formal medical institutions and pharmaceutical companies; (3). As an intermediary to alleviate tensions between the public and patients.

6.1. A welfare arm of the local government

Similar to many other countries, the emergence of SCRC itself can be interpreted as a bottom-up social response to the structural provision gap (Robinson & Henry, 1977). From 1949 to 1978, China had a socialist medical system, in which urban residents relied on state-owned units to seek medical resources. After 1978, the state-owned unit system collapsed and was no longer responsible for people's medical expenses. Patients had to pay for themselves. Starting from 1978, the individual out-of-pocket cost kept increasing, with their share of total medical costs climbed to a peak of 60% in 2002–2003; while governmental spending gradually declined from 1978 to 2000 (Yao, 2017:77–78). This has resulted in a large number of people being unable to afford medical care. One of the interviewees said "We would not have gone to the hospital if there was a choice; thus, many of us were diagnosed with cancer at the last stage."

SCRC does a lot for its members. Patients are invited to join the SCRC for Qigong training and further assistance. Assistance includes peer care, emotional support, and sometimes financial support. The first two types of assistance have been discussed in the section on group cancer-fighting method. Financial support, for which only SCRC members are eligible,

usually applies to two situations — "both husband and wife have cancer" (*shuangai jiating*) or "those with cancer who have no family" (*guguai*). The average amount offered is CNY 500 to CNY 1,000. In some special cases, SCRC organizes donations for patients who are in extreme financial hardship. In addition, SCRC also helped a number of cancer patients who are those sent-down youth, to move their own household registration (*Hukou*) back to Shanghai to receive medical benefits.

In its early days, SCRC provocatively advocated for patients' rights within the political system. In June 1991, SCRC conducted a survey of a sample of 150 out of 2,000 members and wrote a letter to the City Office, "Confusion and Voices of Cancer Patients". In March 1994, SCRC submitted another letter to City Office, "Another Letter to City Leaders". In February 1996, the Shanghai Charity Foundation and the General Union allocated 50,000 CNY (7,670 USD) and 100,000 CNY (15,340 USD) respectively to SCRC to financially support 243 especially needy patients. They also contributed significantly to the push to include cancer drugs in government health insurance.

In summary, the SCRC functions as a patient-led organization in several ways. First, the SCRC plays an important role in gathering and coordinating patients' ideas, balancing individual values and organizational interests in the negotiation process, and taking ultimate collective action. Second, the SCRC can quickly unite and form a unified will whenever a response to a public event is needed. For example, during the COVID-19 pandemic lockdown, they quickly formed an organizational whole to provide the very basics for individual cancer patients. For example, by leveraging their established network with hospitals, communities, and local government officials, they were able to help arrange a green lane for emergency recurrence patients.

6.2. A collaborator with medical institutions

As the only cancer patient-led organization in Shanghai, SCRC has been an important collaborator with different public or private medical institutions. There are varied ways of collaborations. The most common way is to work with hospitals. Its main purpose is not to reduce the high costs or enhance their access to the services, which is beyond the reach of any patient-led organizations. Instead, it set up Cancer Patient Resource Centres. For instance, SCRC set up those centres at eight general hospitals in Shanghai. Two of the eight hospitals do not have separate volunteer management office, allowing SCRC to manage all volunteers related issues. The remaining six hospitals have their own volunteers' offices and supported by SCRC. In our fieldwork observations of the operations of the SCRC operated centres at the hospitals, we found that about thirty volunteers were working daily on a rotating basis. The volunteers follow up on cases and provide further assistance to patients after surgery and radiation therapy. Most of these survivor volunteers are welcomed at the hospitals. As one informant shared with us, "We've been through all of this, and we know what to do to have the best chance of survival. So, some of us, those experienced survivor volunteers would give advice to new patients." One doctor we interviewed also said, "Patients trust the words of survivor volunteers more than doctors." The patient's family also said, "One word from a survivor volunteer is more effective than a hundred words from us."

In addition to providing support for patients undergoing treatments, SCRC is also involved in developing its hospice services. Although Shanghai was one of the first cities in China to establish hospice care in 1988, however, hospice or palliative care in Shanghai still lags far behind the needs of the population. In 2019, only 70 hospitals offer hospice services, either as in-patient specialized unit or by allocating several separate beds within a unit as specialized bed for hospice care. And the situation is getting worse. On the one hand, the increasing aging of the population, and the rising number of cancer patients in China have led to growing demand for hospice and palliative care services. On the other hand, since the market-oriented reform in 1982, hospitals have to be self-financing. Hospitals cannot make profits because patients in hospice services are no longer receiving life-prolonging treatment. If hospitals do

not receive adequate subsidies from the government, the number of berths for palliative care will be cut. Recognizing the needs of these patients, cancer survivors, who have received some basic training, formed a Hospice Care Team (*linzhong guanhuai xiaozu*) to visit and care for those who need palliative care.⁴⁴

Being a collaborator does not indicate that SCRC has assumed a passive position. Our field research shows that SCRC often leads the initiation of new programs and enhances the organization's reputation in this way, a reflection of Yuan's charisma. For example, SCRC initiated a new project called "Medical House Care" (*yihu jiazheng*) with the support of hospitals and community health care centres. The project mobilizes volunteers to make home visits to all kinds of patients, with a special focus on elderly without family support and those in need of long-term care.⁴⁵ Hospitals have generally welcomed the initiative. For example, Tong Ren Hospital (*tongren yiyuan*), one of the reputed hospitals in Shanghai Changning District, not only embraced the initiative but also helped SCRC established regular collaborative agreements with at least ten community health care centres. SCRC helps these public medical institutes reduce the cost of organizing volunteers, provide social support, and mitigate potential conflicts.⁴⁶

SCRC's group cancer-fighting philosophy and methods have attracted the interest of researchers including those from Fudan University and Tongji Hospital. In this case, SCRC works closely with these institutes to evaluate the effectiveness of its method. In a collaborative study with the School of Public Health at Fudan University, the research team was able to demonstrate the positive intervention of a group-centred method on survival rates of cancer patients. They evaluated the impact of SCRC's three-week training program on patients. Pre and post tests were performed, and the results showed that those who participated in the training program had significantly improvement in quality of life after three weeks. And after six months, sleep quality became better due to a dramatic change in exercise duration and intensity.⁴⁷

Although our fieldwork and interviews did not capture sufficient data on the relationship between SCRC and the medical and pharmaceutical industries, the limited data available suggest that SCRC has developed a complex relationship with the medical industry since its inception. Private companies have provided financial support for SCRC operations. On February 12, 1991, Shanghai Hualian Pharmaceutical Co., Ltd. (*shanghai hualian zhiyao youxian gongsi*), a local pharmaceutical manufacturer in Shanghai, established the San Jian Cancer Foundation (*sanjian kangai jijin*). From 1991 to 2000, the foundation had regularly donated money to SCRC.⁴⁸ In recent years, SCRC has also received donations from Shanghai Zhanwang Health Management Co., Ltd. (*shanghai zhanwang jiankang guanli youxian gongsi*) and Shanghai Fangxin Technology Co., Ltd. (*shanghai fangxin keji youxian gongsi*). Accepting funding from drug companies can have negative consequence for patient-led organizations.⁴⁹ When asked if accepting funding from these private companies would harm SCRC as a patient-led organization, President Yuan replied: "I have been very careful to select those drug companies that provide us with funding to ensure that we do not sell our souls".

6.3. A mediator between the public and patients

According to several senior members of SCRC, there used to be a social stigma attached to cancer patients, especially in the early days. The club was originally formed in an alley (*nongtang*), a unique feature of traditional Shanghai neighbourhood, and by extension, a community centred around an alley or several interconnected alleyways. One senior member told us that the residents nearby were always complaining — 'Why are there so many cancer patients? They must be polluting the air. I don't even dare to open the door or dry my clothes in the sun.' Although cancer is not an infectious disease, it seems common for ordinary people to keep their distance from the sick. SCRC was almost forced to relocate. After a report in the *Liberation Daily*, Shanghai Television produced a TV series with the same title as the news report, "True Warmth Exists in our Society" (*renjian ziyou renqing zai*) starting in August 1990. The TV series interviewed hundreds of members of the cancer club, which reveled their hardships. The TV series was nominated for the Shanghai Drama Magnolia Award (*Baiyulan Jiang*).

Although SCRC rarely advocates for any policy related recommendations, it promotes the rights and status of cancer patients through official channels. As we have discussed before, its 1991 launch of the "Selection of Cancer-fighting Stars" campaign was quite successful. It attracted more than 1,800 applications from all over the country. And in 1992, SCRC invited the *Liberation Daily* and the Shanghai General Labour Union to co-host the award ceremony. And to publish another feature article and invite Shanghai Television to produce a feature film named 'Light of Life'.⁵⁰ The recipients of the cancer-fighting Stars then received invitations to give speeches and tell their stories of fighting cancer. One of the interviewees told us that wherever they went, as soon as they opened their mouth and said 'I survived, you will too', or 'My today is your tomorrow', they would immediately receive a round of applause. These cancer-fighting stars will be groomed to become future leaders of SCRC or to replicate the SCRC model, known as Shanghai model, in their own cities. According to SCRC, their model has influenced more than 100 patients-initiated organizations nationwide over the past thirty years.

SCRC presents a new image of cancer patients. They are no longer people waiting to die on a cold hospital bed, but people who enthusiastically embrace life. During the fieldwork, a staff member introduced a documentary film called "Sweet Time" (*tianmi shiguang*). The documentary was produced by the Shanghai TV documentary channel in 2014. The film documents the lives of four cancer patients at SCRC. They recalled the most precious memories in their lives. Perhaps, one of SCRC's most valuable contribution to these cancer patients are the words of one patient at the end of the film: "Our club gives me the confidence to be myself (after getting cancer)." Moreover, SCRC acts as a mediator between patients and doctors. Patients are educated in the club, and through group therapy, they can build better relationships with their doctors and the hospitals. All of this grassroots work do reduce patient frustrations and even irrational behaviours such as verbal and physical violence against doctors.

7. Conclusion

The Chinese medical reform and widespread medical violence against medical staff often distracts people from looking at vibrant patient-led organizations. In this study, we move beyond the rights-based advocacy or information sharing types of patient activism in liberal societies. Instead, we go further to understand the frustrations and achievements of patient activism in the tightly controlled Chinese society. We examine the formation, operation, and practices of China's largest and oldest patient-led organization, the SCRC. Although SCRC does not position itself as

⁴⁴ "Shanghai tuichu anning liaohu xinmoshi" (New Model of Hospice in Shanghai), <http://news.sohu.com>, January 8, 2007. <http://news.sohu.com/20070108/n247481977.shtml>. Accessed May 14, 2019.

⁴⁵ "Duoyuan duoziyuan hezuo chuangshe shuangfang fuwu wufeng lianjie zhiliao he kangfu" (Connecting treatment and recovery for cancer patients in Shanghai), www.shanghai.gov.cn, April 16, 2019. Accessed May 14, 2019.

⁴⁶ "Diyijia aizheng bingren ziyuan zhongxin" (The first Cancer Patient Information Centre). *Shanghai Dangan Xinxi Wang*, 13 March 2008. http://www.archives.sh.cn/shjy/shzz/201203/t20120313_7439.html. Accessed May 14, 2019.

⁴⁷ Wang et al., 2016.

⁴⁸ "Shanghai aizheng kangfu julebu dashiji" (Memorabilia of Shanghai Cancer Recovery Club). *Shanghai Cancer Recovery Club*, June 19, 2007.

⁴⁹ Ozieranski et al., 2019.

⁵⁰ "Shanghai aizheng kangfu julebu dashiji" (Memorabilia of Shanghai Cancer Recovery Club), http://www.shrcr.cn/webs/news_detail.aspx?id=247. Accessed May 14, 2019.

either a patient rights advocacy organization or a social movement aiming to change the existing medical institution, it is neither a GONGO nor a passive affiliated organization. As a grassroots organization, SCRC can still be seen as general patient activism in which patients come together to empower themselves and exchange information. SCRC has shown us several unique characteristics.

First, SCRC advocates a Chinese communist-styled group cancer-fighting method. The whole principle of the group cancer-fighting method is centred on the importance of collectivity, and the spirit superiority. Although patients are not discouraged to adopt Western medical treatments, SCRC asserts that Western medical treatments are not sufficient to overcome the disease. Second, we found that SCRC's organizational structure and organizational culture highly resembled the party state's *tiao-kuai* system. It achieved a high level of vertical and horizontal integration through its three levels (city, district, and street) offices. This system allows it to track the status of its members. We interpret their organizational imitation as an institutional isomorphism to the ideological culture of the party state.

Our findings also echoed existing research that NGOs and social organizations in China are often an extension of government's welfare arm. SCRC contributes to overall welfare by first providing medical consultation and services to patients. Through its education and cultural activities prevailed to patients, SCRC also helps to stabilize patients' anxiety and frustration with the medical system. What surprised us, however, was the social stigmatization of cancer patients and patient-led organizations. In this regard, close collaboration between SCRC, local governments, official media, and industry has been quite successful in changing public perceptions of patients, and patient-led organizations. This partnership also had an unexpectedly positive effect during the COVID19 Pandemic, when SCRC utilized its volunteer network and organizational strength to help district governments monitor the health status of patients.

Lastly, despite China's relatively strict regulation on civil associations, patient-led organizations are still budding. SCRC and the Shanghai Model show us that close cooperative relationships are possible when service oriented social organizations are led by retired communist cadres and the communist ideology and symbols are infiltrated into the fabric of organizational life. The Shanghai model, including its conservative nature, is an important reason for its operational viability under China's strong political control. However, our fieldwork does show that grievances and complaints emerge more frequently than we thought. Will younger leaders continue this model when their charismatic leader steps down? This requires further studies on the evolution of these patient-led organizations. We thus call for future studies to focus more on the organizational level of patient life in non-liberal societies in order to understand the sophisticated interactions of patient life with state power in a wider scope.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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