

Shared decision-making in the People's Republic of China: current status and future directions

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Background: Severe insufficiencies in the supply and inequities in the distribution of health care professionals, facilities, and services create conditions for limited quality of care and lack of trust – even violent conflict – between clinicians and patients in the People's Republic of China. Alongside structural reform, shared decision-making (SDM) may help meet the needs and advance the goals of each patient. Little is known, however, about the realities and opportunities for SDM in the People's Republic of China.

Methods: To identify reports of SDM in the People's Republic of China, we used multiple sources, including: several databases, searched in English and Chinese, online journals, and clinical trial registries. In addition, we contacted experts in the field to identify any articles missed through our other search strategies. We included all trials and surveys reporting on SDM in Chinese patients. We summarized these studies by describing them with particular attention to reports of patient decisional preference and of the impact of SDM interventions on outcomes in Chinese patients.

Results: We identified five surveys examining patient preference for SDM and nine studies examining constructs related to SDM in Chinese patients, but none involving patients in Mainland China. We could not find any reports of development, testing, or implementation of SDM tools for patients in Mainland China.

Conclusion: The research on SDM in the People's Republic of China is limited, with almost no direct evidence to inform clinical policies or implementation. Although multiple barriers are apparent, the value of implementing, testing, and disseminating effective SDM in the People's Republic of China in terms of patient experience and outcomes demands urgent realization.

Keywords: shared decision-making, the People's Republic of China, patient-centered care

Introduction

Shared decision-making (SDM) refers to the work that patients and physicians do together to arrive at a medical decision that reflects the best available research evidence and the preferences and values of the informed patient. The process used to arrive at this decision – sharing information, collaborating and deliberating about the options, and deciding¹ – requires physicians to respect patients and acknowledge the areas about which patients have particular expertise (eg, information about their context, values, and preferences). It also involves some degree of support for patient autonomy and self-efficacy so that they, the patients, are able to take action and face any intended or unintended consequences.

Many decisions in medicine involve uncertainty about which treatment is better. This uncertainty arises from gaps in the evidence or variation in preferences about closely matched alternatives as well as the effects on individuals. SDM seeks to arrive at the best option for a specific patient, with the physician often leading the conversation and empathically engaging the patient to the extent they want to engage

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and participate in the process. This approach differs significantly from traditional practices, in which physicians often act in a paternalistic and expedient fashion, deciding for their patients.

This would not be problematic if fateful decisions were technical in nature (ie, not sensitive to values and preferences, eg, which size stent to use), if physicians and patients shared values and preferences, and if lack of patient involvement was inconsequential. Starting in North America and Europe, medicine has been moving away from paternalism and toward SDM, with patients playing a more important role in their own medical care.²

A key component of SDM is trust.³ A physician must respect the patient, their goals and preferences, which might improve patient's trust;⁴ this respect must arise from a physician's ethical responsibility and training and, in some cases, as a direct consequence of a long-standing relationship with the patient.⁵ Physicians' respect should also manifest as restraint in leading the patient to a particular option and as support as patients struggle to overcome the power gradient between patients and clinicians to make their views known.⁶

Trust is an essential ingredient toward a productive and therapeutic patient–clinician relationship. There is a “trust crisis” in Chinese health care which manifests most notably as violence perpetrated by patients and families toward medical staff.⁷ Although this is not unique to the People's Republic of China,⁸ the magnitude and widespread nature of this crisis argues strongly for innovative solutions. Among those solutions, embedded in urgent structural reform of health care in the People's Republic of China, are those that directly target the patient–clinician interaction. SDM may contribute to improving the trust between patients and clinicians,⁹ while translating evidence into patient-centered care.¹⁰ Yet, all these views about SDM come from literature describing and analyzing clinical care decisions in North America, Europe, and Australia. Yet, little is known about the state of research and practice of SDM in Mainland China. In this article, we will examine this opportunity, review what is known about SDM in the People's Republic of China, and identify areas in need of further work.

Methods

Literature identification

We designed and conducted a search strategy using methods recommended by the Institute of Medicine,¹¹ which includes a search of several databases including: PubMed, Scopus, Ovid MEDLINE, Ovid EMBASE, Ovid EBM Reviews CENTRAL, CINAHL, and Ovid PsycInfo. We

also searched several Chinese databases including: Wanfang, CNKI, SinoMed, NSTL, CSCD, CBMdisc, and Science and technology magazine online. The databases were searched from the time of their inception to 2014. The initial electronic search strategy was supplemented by screening of reference lists from eligible studies. In addition, we reviewed the reference lists from reviews of the topic. There were no language restrictions. The subject terms or keywords used to retrieve the literature denoted the concepts of SDM (including decision-making), SDM tools (eg, decision aid), and in the People's Republic of China.

Article selection

Eligible studies were about SDM in Chinese patients, with either observational or experimental designs. Two reviewers working independently selected eligible studies.

Data collection

We collected the general characteristics of each study (authorship, date of publication, design), methodological details (eg, for surveys, sample size, target participants response rate; for experimental studies, design, interventions and control, primary endpoint), and pertinent results. Data extraction was completed independently and in duplicate.

Analysis

Given the paucity and inconsistency of available studies, we performed a descriptive analysis.

Results

We identified five surveys examining patient preference for SDM and nine studies examining constructs related to SDM (Tables 1 and 2). We describe these studies grouped by type.

Shared decision-making in the People's Republic of China – patient preferences for participation

We found one survey about the SDM preferences of patients from the Mainland China.¹² This report, published in Chinese, included a survey of 565 patients (response rate 94%) receiving care at a large teaching hospital in Western China. Although respondents were representative of the general population in terms of sex and occupation, they were younger, more educated, and were enrolled in commercial health insurance. Of those, 68% had some knowledge of their disease, 93% were willing to participate in clinical decision-making, 89%–95% wanted physicians to seek their opinion

Table 1 Chinese patients' participation in shared decision-making

Author and date of study	Sample size	Response rate (%)	Study design	Type of participation	Outcome measure	Results	P-value
Lam WWT et al (2003) ³⁵	172	89.5	Private face-to-face interview	Chinese patients within 12 days after BC surgery	Perceived involvement in TDM	55% (84/154) were offered a choice of BC surgery. 51% (43/84) of whom indicated that their surgeons expressed a preference for surgery type. Of women who were given a choice, treatment choice did not differ based on time of decision (immediate or delayed). 59% (91/154) want shared TDM.	–
					TDM participation preferences	Preferred TDM roles only differ by age. Women preferring a collaborative role were younger (mean age =50.08 years) than those preferring a passive role (mean age =58.83 years). 80% (124/154) know their surgeon's treatment preference.	0.02
					Perceived PC in TDM	No significant difference was found in perceived PC by age, education, time from diagnosis to treatment, nor by immediate versus delayed choice. Perceived PC differed based on expressing a preference for surgery type by their surgeons (with or without).	0.029
						More women not offered treatment choices (11%) felt that they were not at all-, or under-involved compared to those offered treatment choices (2%). More women offered treatment choice (22%) felt over-involved compared with those not offered treatment choice (3%).	–
					Patients satisfaction with TDM	Women reporting PC had fewer difficulties in TDM than women not reporting PC. Decision barriers and decision facilitators subscale scores were significantly predicted by perceived PC.	0.009
						Under-involved women perceive a lack of time and information to make their decision.	<0.001
						Satisfaction was unrelated to PC.	<0.001
Lam WWT et al (2005) ³⁶	22	100	Tape-recorded, private 45–60 minutes, in-depth, semi-structured interview	Chinese women recently diagnosed with BC	BC TDM experiences	Over-involved women had more doubts about their choice. A four-stage decision-making model was derived as a likened gambling. Two causal conditions influenced TDM process: 1) discovery of a breast abnormality and 2) emotional responses to the diagnosis of BC. TDM process is exemplified by the following experiential elements: indecisiveness, prioritizing personal aims, seeking and evaluating information, and time pressure.	–
						Consequences of making the treatment decision: fear of death, paying the price of the treatment choice, and living in uncertainty.	0.005
						Coping strategies with uncertainty: keeping busy, being optimistic, fatalism, and social comparison.	–
Zhang Q et al (2010) ¹²	600	94.17	Anonymous self-administered questionnaires	Chinese patients in clinic	Knowledge of their diseases	67.27% had some knowledge of their disease. Only 7.45% had more knowledge of their condition. More educated (high school and above) patients tend to have more knowledge about their disease.	–

(Continued)

Table 1 (Continued)

Author and date of study	Sample size	Response rate (%)	Study design	Type of participation	Outcome measure	Results	P-value
Zhang M et al (2006) ³⁷	780	62%	Questionnaire study	Chinese doctors at different level (70% internal medicine, 22% general surgery, 8% gynecology)	Shared decision-making participation preferences	They were usually known the treatment information of their disease treatment from doctors (46.21%).	–
					Patients' satisfaction with their therapy	92.94% was willing to participate in clinical decision-making.	–
						79.20% of all patients surveyed were satisfied with doctors' therapy on them. The first three issues patients were concerned during treatment were curative effect (34.41%), cost (28.41%), and doctors' skill (18.98%). The difficulties that patients concerned in clinic were the limited communication time with doctors (37.08%) and long-time waiting (50.47%). The difficulties toward patient involvement that doctors were most concerned about were lack of time (27%), expressing uncertainties to patients (15%), patient with little medical knowledge (13%), eliciting patients' preferences (12%), and establishing a stable relationship (9%).	–
Lam WWT et al (2009) ³⁸	37	–	Semi-interview following questionnaire	Chinese women with symptomatic BC	Factors influencing delayed presentation	Three factors triggered symptom recognition – symptom interpretation, symptom progression, and social messages. Chinese women make sense of breast symptoms using both traditional Chinese and Western decision rules, which might possibly confuse their symptom attributions, resulting in different causes for appraisal delay. High fear messages can discourage some women and should be avoided in local health education campaigns. Social messages sent via the media facilitate women's prompt utilization of health services on detecting a symptom.	–

Abbreviations: TDM, treatment decision-making; PC, participation congruence; BC, breast cancer.

Table 2 Shared decision-making trials in Chinese population

Author and date of study	Sample size	Response rate (%)	Topic or question being studied	Study design	Primary outcomes	Secondary outcomes	Results	P-value
Lam WWT et al (2005) ²⁰	403	49.13	Identify factors influencing Chinese's choices between BCT, MRM, or MRM followed by MRM + R	198 Chinese women receiving surgery for ESBC who were interviewed face-to-face 1 week post-surgery.	Factors influencing patients' treatment decision	Differences in TDM influences by surgery type	<p>Surgical choice differed by age. Younger women tend to choose MRM + R.</p> <p>Surgeon recommendations significantly influenced women's surgical choice.</p> <p>Women's beliefs about the efficacy of BCT plus radiotherapy varied with the type of surgery they underwent.</p> <p>Image issues (appearance, attractiveness, femininity, and sexuality) and adjuvant treatment issues (avoid radiation therapy) significantly differentiated women making opposing surgical choices after adjustment.</p> <p>Women choosing BCT and those choosing MRM + R rated concerns about maintain femininity, physical appearance, and sexuality as more important compared to women choosing MRM.</p> <p>Women choosing BCT rated avoidance of radiation therapy, further surgery in future, and future cancer recurrence as less important, and attractiveness to husband/partner as more important compared with women having MRM.</p> <p>CHQ12 scores significant decreased from baseline to 8 months.</p> <p>Compared with non-cases or recovered cases, cases at all assessment were significantly younger, had lower self-efficacy, a less optimistic outlook, greater TDM difficulties, and baseline psychological distress.</p> <p>4-month CHQ-12 scores were significantly correlated with TDM difficulties, C-MISS-R, E-OI, C-LOT-R, PSD, and baseline.</p> <p>Compared with non-cases, women meeting moderate/severe or mild case criteria reported greater TDM difficulties, greater baseline psychological distress, and greater PSD.</p>	<p><0.001</p> <p><0.001</p> <p><0.001</p> <p>0.003</p> <p>All <0.001</p> <p>All <0.01</p> <p><0.001</p> <p><0.001 or =0.001</p> <p><0.001 or =0.001</p> <p><0.05</p>
Lam WWT et al (2007) ²¹	405	74.8	The patterns and determinants of longer term psychological morbidity in Chinese women following breast cancer surgery	Chinese women who underwent surgery for breast cancer in six regional Hong Kong public hospitals were enrolled. A baseline face-to-face interview assessment was conducted within 5 days after surgery. Telephone interview follow-up assessment was conducted at 4 months and 8 months post-surgery.	Treatment decision-making difficulty, PSD and psychological morbidity*	Satisfaction with treatment outcome**; ***; self-efficacy****; optimism*****; consultation satisfaction*****		

(Continued)

Table 2 (Continued)

Author and date of study	Sample size	Response rate (%)	Topic or question being studied	Study design	Primary outcomes	Secondary outcomes	Results	P-value
Lam WWT et al (2009) ²²	405	74.8	Social adjustment among Chinese women following breast cancer surgery	Chinese women who underwent surgery for breast cancer in six regional Hong Kong public hospitals were enrolled. A baseline face-to-face interview assessment was conducted within 5 days after surgery. Telephone interview follow-up assessment was conducted at 4 months and 8 months post-surgery.	Social adjustment among Chinese women following breast cancer surgery	The factors predict social adjustment	Enjoyment of social activities and self-image improved slightly. Family interaction and interaction with friends declined slightly. Family and friends interaction subscales were predominantly predicted by high self-efficacy and optimism, whereas self-image and appearance and sexuality subscales were predominantly predicted by low treatment outcome disappointment, TDM difficulties, baseline psychological morbidity, and high self-efficacy. Enjoyment of social activities was predicted by low baseline psychological distress and concurrent PSD.	<0.05 <0.05 –
Lam WWT et al (2012) ²⁷	405	70	Psychological distress among Chinese women diagnosed with breast cancer	Chinese women who underwent surgery for breast cancer in six regional Hong Kong public hospitals were enrolled. A baseline face-to-face interview assessment was conducted within 5 days after surgery. Telephone interview follow-up assessment was conducted at 4 months and 8 months post-surgery.	Psychological distress (CHQ 12)	Satisfaction with TDM, disappointment with surgical outcome, dispositional optimism, and PSD	The predictors of psychological distress were age, education, occupation, and stage of disease. Four distinct trajectories of distress were identified, namely, resilience (66%), chronic distress (15%), recovered (12%), and delayed-recovery (7%). TDM difficulties, optimism, satisfaction with medical consultation, and PSD at 1-month post-surgery predicted psychological distress trajectories. In four-class conditional model, compared with the resilient group, women assigned to the chronic distress, recovered, and delayed-recovery groups reported greater PSD at 1 month post-surgery. In four-class conditional model, the recovered and chronic distress groups reported greater perceived difficulties in TDM in comparison to the resilient group. In four-class conditional model, compared with the resilient group, women in the chronic distress group reported less optimism and women in the delayed-recovery group reported lower satisfaction with medical consultation.	All <0.05 – – <0.001 or =0.001 All <0.001 Both <0.001 Both <0.001

Au AH et al (2011) ^{3,4}	95 (P1) and 38 (P2)	88.4 (P1) and 89.5 (P2)	Assess a DA acceptability and utility among Chinese women diagnosed with breast cancer	A booklet was developed and revised and evaluated in two consecutive pilot studies (P1 and P2). Four-day post- consultation, women newly diagnosed with breast cancer had questionnaires read out to them and to which they responded assessing attitudes toward the DA and their understanding of treatment options.	DA booklet utilization and acceptability	Preparation for TDM, knowledge about breast cancer and treatment, and psychological distress	Most women rated the quality of information either good or excellent in both original and revised draft DA booklets, significantly more women rated the sections on "main differences between treatment options" and "structure guidance for decision-making" in revised draft DA as poor/fair than those in original draft DA booklet. The acceptability of the two DA booklets was high and did not differ. The perceived utility of the DA booklet was comparable between the two pilot studies. Knowledge scores varied with the extent the booklet was read in both pilot studies.	<0.005
							Women reported low levels of anxiety and depression in both studies. There was no significant change in scores for anxiety or depression from baseline to follow-up interview after adjustment for reading, for either version of the DA booklet.	<0.001 in P1 and 0.034 in P2 All >0.05
							Distress trajectories over the first 8 months postoperatively predicted psychosocial outcomes 6 years later. Women with stable low levels of distress over the first 8 months postoperatively (resilient group) had the best 6-year psychosocial outcomes. Women who experienced chronic distress had significantly longer term psychological distress, cancer-related distress, and poorer social adjustment in comparison to women in the resilient group.	<0.01
							Women in the recovered or delayed- recovery groups were comparable to those in the resilient group, except for concerns about appearance and sexuality, and self- image.	<0.05
Lam WWY et al (2012) ²⁵	303	65.3	Distress trajectories at the first-year diagnosis of breast cancer in relation to 6-year survivorship	Chinese women recruited 1 week post-surgery for predominantly ESBC were assessed for distress with the Chinese Health Questionnaire at 1 month, 4 months, and 8 months later. Latent growth mixture modeling revealed four distinct distress trajectories during the first 8 months following surgery. A follow-up telephone interview was re-contacted between 5 years and 6 years post- surgery.	1–8-month distress trajectories in relation to 6-year outcomes	Demographic and medical variables in relation to 6-year outcomes	–	

(Continued)

Table 2 (Continued)

Author and date of study	Sample size	Response rate (%)	Topic or question being studied	Study design	Primary outcomes	Secondary outcomes	Results	P-value
Lam WWT et al (2012) ²⁶	471	89.4	The validity and reliability of the Chinese version of the DCS in Chinese women deciding breast cancer surgery	A Chinese version of the 16-item DCS was administered to 471 women awaiting initial consultation for breast cancer diagnosis. CFA assessed the factor structure. Internal consistency, and convergent and discriminant validities of the factor structure were assessed.	Psychometric assessment of DCS	Decision regret scale, perceived TDM difficulties scale, medical interview satisfaction scale, and hospital anxiety and depression scale of DCS	The overall reliability for the 14-item version of the three-factor hierarchical DCS was high. All of the DCS-14 subscales and the overall scale demonstrated an expected moderate correlation with the measure of perceived difficulties in TDM.	$r=0.36-0.53$
							All of the DCS-14 subscales and the overall scale correlated positively with the concurrent measure of anxiety, depression as well as negatively with the measure of patient satisfaction with medical consultation.	$r=0.20-0.42$, $r=0.21-0.41$ and $r=0.37-0.52$
							All of the DCS-14 subscales and the overall scale showed positive correlation with the measure of depression and the measure of decision regret assessed at 1 month postoperatively.	$r=0.14-0.25$ and $r=0.10-0.26$
							With the exception of the uncertainly and effective decision subscale, other subscales and the overall scale correlated positively with anxiety scores measured at 1 month postoperatively.	$r=0.20-0.27$
							Congruent with expectations, delaying decision makers reported significantly higher scores on all of the DCS-14 subscales and the overall scale than non-delaying decision makers.	<0.05
							Most women (63.5% self-image; 57.6% sexuality) showed stable levels of self-image and sexuality scores.	–
							Self-image trajectories over the first-year diagnosis predicted 6-year psychosocial outcomes.	<0.001
							Low TDM difficulties and high treatment outcome satisfaction predicted high and stable self-image and sexuality.	<0.001
							Self-image during acute illness phase predicted long-term outcomes.	–
							Appearance and sexuality trajectories did not predict 6-year outcomes.	<0.05
Lam WWT et al (2012) ²³	363	84	Trajectories of body image and sexuality during the first year following diagnosis of breast cancer and their relationship to 6-year psychosocial outcomes	Chinese women who underwent surgery for breast cancer in six regional Hong Kong public hospitals were enrolled. A baseline face-to-face interview assessment was conducted within 5 days after surgery. Telephone interview follow-up assessment was conducted at 4 months and 8 months post-surgery. A follow-up telephone interview was re-contacted between 5 years and 6 years post-surgery.	Self-image trajectories, sexuality trajectories, and their relationship to 6-year outcomes	–		

Lam WWT et al (2013) ²⁸	276	81.5	To assess if a DA could reduce treatment decision conflict difficulties in breast cancer surgery	Women were block randomly assigned by week to either an intervention (DA, take-home booklet) or control (standard information) arm after the initial consultation. Participants completed interview-based questionnaires 1 week after consultation and then 1 month, 4 months, and 10 months after surgery.	Decision conflict, decision-making difficulties, BC knowledge 1 week after consultation and decision regret 1 month after surgery	Treatment decision, decision regret 4 and 10 months after surgery, and postsurgical anxiety and depression	Decision-making difficulties 1 week after consultation did not differ between the DA and control arms. Patients in the control group reported significantly greater decisional conflict 1 week after consultation than patients in the DA group. Levels of knowledge about BC and its treatment 1 week after consultation did not differ between the DA and control groups. Decision regret 1 month after surgery did not differ between groups. Patients in the control group reported significantly greater decision regret 4 months and 10 months after surgery than patients in the DA group. HADS depression scores 4–7 days and 1 month after surgery also did not differ between groups. 10 months after surgery, patients in the control arm reported significantly greater HADS depression scores. Choice of surgery and reconstruction did not differ between the DA and control arms.	0.064 0.016 1.000 1.000 0.026 and 0.014 0.849 and 0.649 0.001 0.663 and 0.131
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Notes: *CHQ12 scores, **BCDMQ, ***E-OI, ****GSeS, *****CLOT-R, *****C-MISS-R.

Abbreviations: CHQ, the Chinese health questionnaire; BCDMQ, the Breast Cancer Decision Making Questionnaire; E-OI, Expectancy-Outcome Incongruence; GSeS, General self-efficacy Scale; CLOT-R, the Chinese revised Life Orientation Test; C-MISS-R, the 8-item Chinese-validated version of the Medical Information Satisfaction Scale (revised); BCT, breast-conserving therapy; MRM, mastectomy; MRM + R, MRM followed by breast reconstruction; TDM, treatment decision-making; PSD, physical symptom distress; DA, decision aid; P1 and P2, pilot 1 and pilot 2; ESBC, early-stage breast cancer; DCS, decisional conflict scale; CFA, confirmatory factor analysis; HADS, Hospital Anxiety and Depression Scale; CHQ12, means the Chinese health questionnaire.

when making decisions about their care. Table 1 shows the results of surveys of Chinese patients' preferences for participation in decision-making, with most studies reflecting the preferences of Chinese people from Hong Kong and these findings are similar to the preferences of patients in North America and Europe.^{13–18}

Shared decision-making interventions

We could not find any studies of SDM tools or interventions developed or tested to promote this process in Mainland China. No data was found related to SDM or decision-making in Chinese patients in Mainland China. However, nine studies were found that examined constructs related to SDM among Chinese living in Hong Kong. The population examined in these studies consisted mostly of women with breast cancer.^{20–27} These studies reported on the value of existing measures of decision-making in this population and correlated the quality of decision-making about breast cancer treatment with distress and long-term satisfaction.

Discussion

Statement of findings

In this review, we found that little is known and documented about SDM in Mainland China, with very sparse evidence – qualitative or quantitative – about the feasibility, cultural and structural fit, processes, and outcomes of SDM in Chinese patients. We did find that Chinese patients of high socioeconomic status are similar to their counterparts in North America with regard to autonomy and the desire to be involved in medical decisions that affect their lifestyle and outcomes. However, because these respondents do not represent the general population of Mainland China, little is known about the decision-making role preference of patients in Mainland China.

Limitations and strengths

Almost all participants in the identified surveys must imagine SDM to express preferences for which it reduces the validity of measurement. While this limitation affects nearly all surveys of patient preferences for SDM, this may be more so in the People's Republic of China. This is because the concept of SDM is interpreted differently in various social and cultural contexts.¹⁹ In the People's Republic of China, medical decisions are often influenced by diverse concepts of social harmony and respect for one's elders, which might be related to different religious or moral codes. An additional barrier to assessing preferences for SDM is disclosing diagnoses to patients with serious diseases, such as cancer,

as often both physicians and patient's families avoid telling the patient about serious diagnoses. Therefore, it is difficult to know for sure the extent to which Chinese people would consider SDM, as experienced in North America and Europe, for example, culturally and individually desirable. Most of the available evidence reported here involves Chinese women with breast cancer in Hong Kong. These studies were conducted by the same researchers using small samples and heterogeneous methods. This fuels optimism about the feasibility of SDM in Mainland China.

Yet, due to regional disparities in the People's Republic of China, geographically focused health services and survey research may help determine how best and to what extent patients and clinicians can and will take part in SDM across different health care contexts and across regions in the People's Republic of China. Careful qualitative research to understand how SDM should be understood in the Chinese context may represent an important prerequisite to the empirical task of promoting SDM in the clinical encounter. Such data are not available. Our thorough search strategy, including databases of literature in Chinese, reduces but cannot eliminate the likelihood that we may have missed other studies. To our knowledge, this is the first attempt at systematically summarizing the available literature of SDM in the People's Republic of China and to identify the opportunity gaps in this area.

Implications for policy and practice

The health care system in the People's Republic of China faces many challenges. The main issue is the lack of sufficient health care resources to meet the needs of its expanding population. There are 260 million patients living with chronic disease.²⁹ The People's Republic of China aging population is estimated to increase at a rate of 5.96 million per year from 2001 to 2020. Although the total amount of medical resources per capita has increased, it is still relatively low in the People's Republic of China compared with most developed countries.³⁰ This lack of resources coupled with the poor health literacy and unrealistic expectations of patients (eg, expectation for the newest drugs/technologies without understanding of risks/benefits/access limitations) has led to overwhelmed physicians and widespread frustration and dissatisfaction among patients.

For example, in the large hospitals, on average, a physician must treat more than 100 patients every day – this translates to approximately 5 minutes spent with each patient. Consequently, the time for communication is limited; physicians have little time to gather information about the patient

and to make a diagnosis, to share information about the patient's condition, to share information about the available treatment options, or to share the decision-making process with their patients. This pressure may result in misdiagnoses and low-quality care. Hospitalized patients may find that Chinese physicians are highly skilled in medical techniques, but less skilled in communication. This may be due to the absence of humanities education for medical students in the People's Republic of China.³¹

Given the growing insufficiencies and inequities of the Chinese health care delivery system, low health literacy of the Chinese populations, extremely brief encounters, and the state of distrust and disrespect between patients and clinicians, SDM may not be within reach. Furthermore, cultural differences may require SDM to assume different forms compared to SDM tools and procedures developed in North America, Europe, and Australia. For example, while individual autonomy is typically held as a key bioethical principle, the collectivistic nature of Chinese culture often leads to a decision-making process where the individuals' preferences are informed by and may even be secondary to the preferences of their friends and family. On the other hand, the survey results reviewed here show that Chinese patients of high socioeconomic status are similar to their counterparts in North America with regard to autonomy and the desire to be involved in medical decisions that affect their lifestyle and outcomes. Because these survey respondents did not represent the general population of Mainland China, however, little is known about the decision-making role preference of patients in Mainland China.

Furthermore, the successful implementation of SDM will need support from policy makers, particularly the Chinese government. The Malaysian experience in SDM implementation, a pioneering one in Asia, offers a likely applicable example.³² Similar to what we found, very few studies have examined SDM in Malaysia. Existing studies showed that doctors were aware of informed consent, but few practiced SDM. Professional medical bodies endorsed patient involvement in decision-making, but there was no definitive implementation plan. However, the authors have provided a set of recommendations on how SDM can be effectively implemented in Malaysia through education, clinical practice, research, and policy and law. The conditions and culture are similar enough between the People's Republic of China and Malaysia that this experience may apply to Mainland China. Government support may include investments to improve access and quality of care in community settings and better access to and affordability of

important evidence-based treatment options, especially in rural areas. In addition to improving the context for SDM to flourish locally, these changes may also promote SDM in the referral urban hospitals by reducing demand for specialized care, resulting in longer appointments.

Implications for research

While the practice of SDM faces major barriers, research around SDM may be easier to accomplish. Observational studies to understand how decisions are being made across contexts and settings could help establish a baseline and help make the case for SDM. Understanding the professional and patient levers for SDM could also be fruitful. For example, specific and teachable physician–patient communication behaviors, including SDM, are associated with fewer malpractice claims for physicians.³³ Although the experience from USA may not generalize to the People's Republic of China, because there is no related study in the People's Republic of China, it is worth implementing SDM in the People's Republic of China. Thus, Chinese physicians concerned about the impact of malpractice risk could be motivated to improve their communication skills, in turn promoting the adoption of curricula in SDM and patient-centered communication in medical schools and postgraduate training programs. Medical sociology studies focused on the work of SDM³⁴ may also uncover the roles that patients and clinicians could play. Design researchers could work together with Chinese patients and clinicians to devise cultural- and context-sensitive tools, training, and services that might facilitate SDM, and subject these to empirical testing. Some insights may emerge from the testing of SDM tools developed elsewhere in usual Chinese practice settings, particularly in relation to the division of labor, how practices deal with the demands for decision-making time, how patients respond to the invitation to participate in choice, and how clinicians and patients handle situations in which they disagree.

Conclusion

While our analysis has focused on Mainland China and its 1.3 billion people, the literature and implications noted here likely apply to the early efforts to promote SDM in low- and middle-income countries with health systems that share the same challenges, if not in magnitude, faced by the Chinese people. In addition to the structural challenges, paucity of research impairs further evidence-based development of SDM in the People's Republic of China, and this needs to be corrected. If successful, SDM may become a more common experience for many patients in the People's Republic of China, which

could contribute to rebuilding the therapeutic alliance of trust and respect between clinicians and their patients. The health, rights, and respect of vulnerable patients and professionals in the People's Republic of China deserve this transformation.

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Disclosure

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