

Self-management following a cardiac event in people of Chinese ethnicity living in Western countries: a scoping review

INTRODUCTION

Cardiovascular disease is a major cause of deaths and disability worldwide [1]. People who experience a cardiac event such as acute coronary syndrome (ACS) including unstable angina, as well as ST-elevation and non-ST-elevation myocardial infarction (STEMI and non-STEMI), often require urgent interventions that include hospital admission and related procedures such as coronary artery bypass graft (CABG) and percutaneous coronary intervention (PCI). ACS is often associated with physical and psychological sequelae including ongoing disease symptoms, reduced physical function, limitation in daily activities [2, 3], and depression or anxiety [4-6]. These physical and psychological changes can also have a substantial impact on the health-related quality of life (HRQoL) of both patients and their families [7, 8].

Recovering from ACS or related procedures, patients learn to adjust to these changes but also need to undertake many behaviours related to secondary prevention including managing their recovery, risk reduction and incorporation of key medications [9]. These behaviours are often referred to as self-management and/or self-care, although the term self-management will be used in this paper. Self-management is commonly understood to involve a variety of activities which protect and promote health such as monitoring signs and symptoms, adhering to treatment, modifying lifestyle, and coping with the impact of disease on personal well-being and interpersonal relationships [10].

Self-management requires a person's capacity to act and make choices and is influenced by multiple factors including knowledge, culture, values, beliefs, language, social-economic status, motivation and self-efficacy [11, 12]. The role of self-management in coronary heart disease recovery and particularly

secondary prevention is important and can have a substantial impact on health outcomes. Appropriate self-management has been proven beneficial in reducing mortality and improving HRQoL [13, 14]. Whereas poor self-management can lead to a high recurrence, hospital re-admission and mortality, as well as poor HRQoL [15-17].

However, the complex nature of cardiac disease and variations in personal capacity mean that self-management can be challenging for patients. Self-management following ACS or related procedures varies by ethnicity and migration status, and ethnic minorities and immigrant groups living in Western countries were found to be disadvantaged compared with the majority of local residents [18, 19]. One example of an immigrant group present in many Western countries is people of Chinese ethnicity. This population is growing rapidly as China has become one of the largest migrant-exporting countries in the world; with more than 50 million ethnic Chinese emigrated in the past century [20, 21]. In this paper, we refer to people of Chinese ethnicity as people born in or having ancestry from mainland China, Hong Kong, Macau, or Tai Wan, but living in a region apart from these areas. They can also be classified as first or second generation immigrants depending upon their own and their parents' birth regions [22, 23].

The prevalence of coronary heart disease increases in people of Chinese ethnicity living in Western countries such as Canada, the United Kingdom, and Australia, compared to those living in China [24, 25]. Furthermore, compared with the majority in host countries, health outcomes, especially the short-term mortality of coronary heart diseases, are worse in this group [26]. These epidemiologic changes are associated with lifestyle changes, stress, financial difficulties, as well as the duration of stay in Western countries [27].

These changes are also potentially due to difficulties in self-management of coronary heart disease for people of Chinese ethnicity which may include the access to and utilization of healthcare, interaction with health providers, and adherence to treatment[19, 28]. Such issues are complex and remain understudied and poorly understood. Therefore it is important to understand self-management and experiences in engaging with the healthcare system in people of Chinese ethnicity living in Western countries after ACS or related procedures, to identify the gap between their needs and what the healthcare system provides, to lay a foundation for developing tailored and culturally appropriate secondary prevention strategies.

AIM

The aim of this review is to explore self-management and experiences with the healthcare system after ACS or related procedures amongst people of Chinese ethnicity living in Western countries.

METHODS

Design

A scoping review was conducted using a systematic approach for the literature search. Scoping reviews were first described by Arksey & O'Malley (2005) and updated by others in the past decade [29, 30]. This is an explorative method, which addresses broad areas of evidence, explores breadth rather than depth, and generally does not require quality assessment, allowing the inclusion of both quantitative and qualitative studies as well as grey literature based on relevance to the topic [29]. This method is appropriate for areas that are understudied and complex and suitable for examining the available evidence and identifying gaps in the literature [31], which makes this method particularly relevant to the complex topic of self-management.

Scoping review steps

This scoping review followed the steps described by Levac et al (2010), namely (1) identifying the research question; (2) searching for relevant studies; (3) selecting studies; (4) charting data; (5) summarising, synthesising, and reporting results; as well as (6) validating the results with a multidisciplinary team including researchers and clinicians.

Search strategies

After identifying the research aim, a literature search using a systematic approach was conducted, which was limited to studies conducted in humans and reported in the English language before December 2015, using the bibliographic databases CINAHL, Medline (Ovid), Scopus, Embase, PsycINFO, and Proquest-Central. Both medical subject heading (Mesh) terms and keywords were used in searching (Table 1).

Duplicates were removed from the initially identified studies. We first assessed titles and abstracts and removed studies that were not relevant to the research question. The remaining studies were assessed in full text in detail and were checked by two independent reviewers (LZ, RG). Any new relevant papers identified in reference lists were then assessed. The studies not meeting inclusion criteria were removed (Figure 1).

Inclusion criteria

- Sample includes patients who have been admitted for ACS including unstable angina, as well as STEMI and non-STEMI, or related procedures such as coronary artery bypass graft (CABG), and percutaneous coronary intervention (PCI);

- Studies conducted in people of Chinese ethnicity living in Western countries;
- Reported post-discharge self-management and self-care behaviours in above heart conditions and/or
- Reported experiences in access and utilisation of healthcare;
- Published in English.

Charting, summarizing, and synthesizing data, reporting and validating results

Data from each paper was charted, subsequently analysed and reported. Information regarding publication, study aim, study design, participants (age, gender), sample size, diagnosis, and main findings was extracted and summarised. After reviewing data and making notes, thematic analysis was used in analysing qualitative data.

An overview of the findings related to patients' self-management behaviours and experiences in accessing and utilisation of healthcare extracted from the studies was categorized into different domains, namely access and utilisation of healthcare, provider-patient interaction and self-care [12]. The first author (LZ) extracted the data, and a second author (RG) independently reviewed the extracted data. Potential disagreements were discussed to reaching consensus. Based on agreed data, patterns and themes were developed.

To validate the results in the last step, seven professionals were contacted to form a multidisciplinary panel, consisting of three senior cardiac nurses and four researchers. The three cardiac nurses, of whom two were Chinese, have extensive experience in caring for cardiac patients of Chinese ethnicity. Of the four researchers, two of whom were Chinese, one having expertise in health promotion, one in cross-cultural qualitative research, and two in cardiac

disease secondary prevention. Uncertain findings were discussed between panel and authors until clarified.

RESULTS

This review included six studies that met the inclusion criteria (Table 2)[19, 28, 32-35]. Of the studies, four were qualitative and two were quantitative. These studies were conducted in Australia (n=1), Canada (n=3) and the United Kingdom (n=2). The sample sizes in the two quantitative studies were 258 and 436 participants and the sample sizes in the four qualitative studies were between 8 and 26 participants [19, 28, 32-35]. Most studies were focused on participants over the age of 65 years. The diagnoses included CHD, ACS, and AMI.

Four overarching themes were found, namely: 1) understanding of heart disease, risk factors and symptom recognition, 2) adherence to medication and lifestyle modification, 3) health service/information choice, and 4) family role in disease self-management and decision making. All themes were greatly influenced by language proficiency and cultural practices.

Understanding of heart disease, risk factors, and symptom recognition

The view of the heart and heart disease was explored in three studies [28, 32, 35]. Chinese participants viewed the heart as a primary organ having physiological and psychological functions. While heart disease was viewed as an acute and serious condition [32, 35], it was viewed as less chronic than osteoarthritis and less serious than cancer [32].

Overall, Chinese participants did not fully understand the causes and risk factors of cardiac disease. The majority of participants in one study failed to identify important risk factors such as being male, over the age of 50, and

having diabetes [35]. Some participants in another study believed that heart disease was caused by family history or stress [28]. 34.9% (n=152) of Chinese participants in the former study were not sure whether cardiac disease is curable [35].

Poor symptom recognition was reported in three studies [28, 32, 33]. No ethnic difference occurred between Chinese and non-Chinese in ACS symptom experience [33]. Although symptom recognition was poor in most participants of minority ethnicities [33], Chinese participants were more likely to ignore or deny the early symptoms of ACS, particularly when symptoms went away or were not intense [28, 32, 33]. Some Chinese participants in one study also tended to link the early symptoms to musculoskeletal problems, rather than to the heart [33].

Adherence to medication and lifestyle modification

Adherence to medication or lifestyle modification was reported in four studies [19, 28, 32, 35]. Chinese participants in one study were found to be less likely to adhere to overall medications, and had particularly poor adherence to ACE inhibitors compared with other ethnicities [19]. Medication adherence among Chinese participants in another study was found to be mainly based on their best interests as well as their symptom experiences [28].

Adherence to lifestyle modification was noted to be largely dependent on one's educational background, personal philosophy, beliefs, experiences, knowledge, and information shared with others [28, 32, 35]. Risk modification approaches often reflected participants' usual approach in decision making and philosophical foundation or faith. When a "straightforward approach" was used in daily life then a rapid dietary change was undertaken after the cardiac event. Whereas those who adopted a "peaceful accepting approach" in daily

life then also accepted their diagnosis and information to help keep a peaceful mind and enhance their health [28].

When Western medicine recommendations were discordant with traditional beliefs, Chinese participants were less likely to follow the Western recommendations. For instance, attending cardiac rehabilitation (CR) became difficult as it was considered to be incongruent with traditional views of resting and relaxation during recovery [32]. Salt reduction became challenging, as many Chinese participants believed that a Chinese diet was healthier than a Western diet [28, 32, 35].

Health service/information choice

The majority of Chinese participants preferred to use bilingual health professionals and were hesitant to use emergency services in an urgent situation. Although Chinese participants respected Western practitioners, they still preferred to go to a Chinese or bilingual physician for interpreting health information, overcoming cultural barriers, and navigating the healthcare system [28, 32, 33]. A bilingual physician was described as “trusted” or “having better understanding” by Chinese participants [28, 33].

The underlying reasons for avoiding emergency services were language barriers, family responsibilities, and fear. Language barriers in accessing emergency services were reported in two studies [28, 33] and Chinese participants in one study tended to go to a Chinese physician and avoid seeking emergency services even in an emergency situation [33]. Using the emergency service was considered to be troublesome to their family for female Chinese participants in this study, they placed family responsibility above personal health needs[33]. Moreover, the fear of going to the hospital

and not coming out of hospital again also caused hesitation in seeking emergency services in some Chinese participants from the same study [33].

Balancing between Western medicine and traditional Chinese medicine (TCM) is an important and common part of self-management in Chinese participants [28, 32, 34, 35]. The decision-making process was influenced by multiple factors such as beliefs and trust level in both medicines [28, 32, 34]. Use of TCM was found to be strongly linked with Chinese traditional beliefs, and it was considered as part of disease management and daily life [32]. Both medicines were used together or alternatively as both types of medicine were considered to have their own advantages [28, 34, 35]. Low level of trust in Western medicine led Chinese participants to seek help from TCM [34].

Although the majority of Chinese participants had high regard for authority and thus health professionals, evidenced by a quicker acceptance of their diagnosis, being diligent about attending appointments and eagerness to learn more information about their disease, in one study some participants were skeptical and selective of the health information provided [28].

Family role in disease self-management and decision making

The marital and familial relationship played a very important role in disease self-management and decision making as reported in two studies [28, 32]. The family role included supporting activities of daily life and assisting in navigating the healthcare system [28, 32]. Male participants tended to get help from their spouses, whereas female participants tended to get help from their children [28]. Moreover, family members had also involved in disease-related decision-making processes, although this was not described in detail [32].

Validation by multidisciplinary panel

The multidisciplinary panel independently reviewed the findings from the literature and provided feedback based on their clinical or research experience and their cultural understanding. The panel was in general agreement on the key findings in relation to aspects of self-management and experiences in engaging with the healthcare system in people of Chinese ethnicity. The panel confirmed the importance of the results in understanding Chinese immigrant patients in their care.

DISCUSSION

To our knowledge, this is the first review of self-management behaviours and experiences in engaging with the healthcare system in people of Chinese ethnicity living in Western countries who experienced a cardiac event or related procedures. The findings reveal some phenomenon relating to the utilisation of the healthcare system, interaction with a healthcare provider, and self-management. Overall Chinese culture was very influential to people of Chinese ethnicity who had ACS or related procedures, and language, beliefs and family values were identified as the most influential factors.

Firstly, limited English proficiency has often been reported as a barrier to self-management, particularly to receiving health information and choosing healthcare [36-38]. Insufficient language capacity often hinders the interaction with healthcare providers. Patients of Chinese ethnicity are significantly less likely to receive or discuss the information about disease and prevention with healthcare professionals compared with other ethnicities. As a result lack of disease and healthcare services information is often observed in this population, particularly in older and recent immigrants [39, 40]. Consequently, when limited English proficiency combines with poor health knowledge, behaviours including non-healthcare seeking, self-diagnosis or self-treatment, delayed healthcare-seeking, and/or poor compliance to treatment are present

[39, 40-45], which often lead to poor health outcomes [46].

These health behaviours may also reflect the low confidence level in utilizing healthcare services by people of Chinese ethnicity [40, 44, 47, 48, 49].

Healthcare seeking among these people is often considered as the last resort [40], and only occurs when the self-treatment fails or when the condition becomes worse, and often requires family members' assistance [44, 47-49].

This behaviour may also partially explain why ethnically and linguistically matched general practitioners are highly preferred by people of Chinese ethnicity regardless of the severity of the medical condition [39, 50, 51].

However, such a specific preference may lead to delays in receiving appropriate treatment, and consequentially worse health outcomes [52].

Secondly, certain Chinese traditional health beliefs have shown to be influential on perceptions of illness/health and TCM/Western medicine amongst people of Chinese ethnicity, further impacting on their choice of type of medicine [53-56]. Beliefs held by this population are often incorporated into disease management, as well as daily life. The cardiac condition is believed as acute rather than chronic in this population. Based on this belief, poor medication adherence is not surprising [53, 55].

Furthermore, the beliefs of Western medicine and TCM held by this population often influence their choice of type of medicines as TCM is often viewed as a cultural heritage and is believed to have fewer side-effects and to treat health problems in a holistic way, which is in contrast to views of Western medicine [54, 56]. In this population, TCM is used as an important resource in many disease's management, as well as in self-treating minor illnesses [56, 57]. A high rate of using TCM is also found in those holding a view that Western medicine cannot completely cure a chronic disease [45, 50], and acculturation

and success experiences with Western medicine do not necessarily discontinue in using TCM in this population [50]. Despite the high rate of using TCM, patients of Chinese ethnicity were rarely informed or assessed regarding their use of TCM by Western medicine practitioners, which might lead to drug interaction or even worse consequences [58].

Finally, the family is a core part of the Chinese value system and it plays an essential role in disease management. This needs to be considered in light of the Chinese value system. Family members are identified as a primary source of social support, playing an important role in supporting disease management and decision-making [40]. Given the role of the family as a central unit in Chinese culture, it is not surprising that family members act as caregivers, providing support and facilitate disease management, as well as making a decision regarding medical treatment [40, 53, 59, 60]. Compare to male, female family members are more likely to take the caregiver role and they are more likely to view the family responsibility beyond their own health needs. Such a view may prevent them from seeking healthcare and silence the suffering [54, 60, 61].

LIMITATION

The limitation of this scoping review is that the included studies do not always describe the post cardiac event experiences explicitly, extensively, or clearly. Therefore bias may have been introduced by the interpretation of reviewers. However, a multidisciplinary team was referred to validate the results in an effort to minimize possible bias.

CONCLUSION

The findings from this review show there are ethnic disparities in self-management and utilisation of health information and resources amongst

people of Chinese ethnicity living in Western countries. These disparities are influenced by English language proficiency and Chinese culture/beliefs, which are deeply embedded in every aspect of disease self-management.

Developing culturally appropriate and sensitive interventions in the Chinese language is needed to improve cardiac disease self-management in this population.

ACKNOWLEDGEMENT

The authors have no financial relationships relevant to this article to disclose.

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Table 1 . Search string of scoping review.

Mesh terms	<p><i>“Asian continental ancestry group” OR “Chinese” OR “transients and migrants”</i></p>		<p><i>“coronary heart diseases” OR “coronary disease” OR “heart disorder” OR “ischemic heart disease” OR “myocardial ischemia” OR “myocardial infarction” OR “acute coronary syndrome” OR “coronary artery bypass graft (CABG)” OR “angina unstable” OR “angioplasty, balloon, coronary”</i></p>		<p><i>“after care” OR “discharge” OR “transfer”</i></p>		<p><i>“health literacy” OR “self-care” OR “social adjustment” OR “psychosocial adjustment”</i></p>
key words	<p><i>“Chinese migrants” OR “Chinese” OR “China”; “ethnicity”</i></p>	AND	<p><i>“heart disease” OR “coronary heart disease” OR “myocardial infarction” OR “heart attack” OR “unstable angina” OR “acute coronary syndrome” OR “CABG” OR “per cutaneous coronary intervention (PCI)” OR “percutaneous transluminal coronary angioplasty” OR “coronary balloon angioplasty” OR “PTCA”</i></p>	AND	<p><i>“after care” OR “discharge” OR “transfer”</i></p>	AND	<p><i>“experience” OR “knowledge” OR “understanding” OR “secondary prevention” OR “recovery” OR “health outcome” OR “adjustment” OR “decision making” OR “care-seeking” OR “health-seeking behaviours” OR “symptom recognition” OR “risk management” OR “medication adherence”</i></p>

Table 2 . Study description and main finding.

References Country	Study Design	Sample Description	Focus	Main findings
[32] Australia	Qualitative study using thematic analysis	All Chinese: n = 78 focus group (68 years mean age), n = 8 individual interview (74 years mean age); n= 13 health professional (44 years mean age)	Post cardiac event experiences	<ul style="list-style-type: none"> • Traditional Chinese view is heart is primary organ so heart disease is a serious condition, but not as serious as cancer or as chronic as osteoarthritis; traditional Chinese medicine (TCM) helps to restore inner balance, recovery and bring sense of coherence. • Traditional beliefs were followed in preference to Western medicine recommendations, so dietary modification and cardiac rehabilitation became challenging. • Medical practitioners were respected but, bilingual practitioners were valued and preferred as mediators between cultures and treatment modalities. • Family is important for support and brokering healthcare system and relied upon for decision-making.
[28] Canada	Qualitative study using grounded theory	15 Chinese participants (age range 53-83 years)	Influence of Chinese ethnocultural beliefs on behaviour change post cardiac event	<ul style="list-style-type: none"> • Some CVD risk factors were identified but lack of understanding of causes of cardiac disease, and belief family history or stress was main cause. • Rapid acceptance of diagnosis and behavior change phase. Risk factor modification usually initiated by cardiac diagnosis or event. • Approach to risk reduction based on individual's education, personal philosophy, beliefs, experiences, knowledge and shared information.

				<ul style="list-style-type: none"> • Self-management based on personal beliefs for adjusting medication, seeking best health care and resources, being selective and skeptical regarding health information and medicine choices. • Great respect for health professionals and diligence in attending appointments and CR. • Marital and familial relationship important in managing CVD risk. • Language barriers posed problems and were overcome by family.
[33] Canada	Qualitative study using grounded theory	20 Caucasian 18 Chinese 19 South Asian (65+years)	Recognition of symptoms, decision-making, and healthcare seeking	<ul style="list-style-type: none"> • All ethnicities had similar process of having symptoms; waiting/denying; justifying; disclosing/discovery; acquiescing; taking action. Care-seeking occurred only when symptoms persistent, intense and pre-exposure to ACS. • Chinese participants, particular females, tended to delay care-seeking and avoid seeking urgent care based on beliefs, family responsibilities or due to misinterpretation of ACS symptoms. • Chinese participants often had language barriers and relied on “trusted” physicians from their linguistic and cultural background to help navigate healthcare systems.
[19] Canada	Retrospective cohort study	9926 acute myocardial infarction (AMI) survivor (65+ years, 258 Chinese, 511 South Asian, and 9157 Non-Asian)	Medication adherence	<ul style="list-style-type: none"> • Chinese and South Asian participants prescribed more medications in three months post-discharge compared to non-Asian. Chinese participants more likely to be prescribed beta blockers. • Chinese participants less likely to be adherent to overall medication (OR: 0.70; 95% CI: 0.51-0.95), and ACE inhibitors compared with non-Asian (OR: 0.53; 95% CI: 0.39-0.73).
[34]	Qualitative	26 Chinese (age was not	Utilisation of health	<ul style="list-style-type: none"> • Variable level of trust in Western Medicine

United Kingdom	study using grounded theory	reported) 7 health professionals	services	<ul style="list-style-type: none"> Both Western and TCM were used intermittently. Discontent with treatment in one resulted in seeking the other.
[35] United Kingdom	Cross-sectional	436 Chinese (18+ years)	CVD knowledge and CR awareness	<ul style="list-style-type: none"> The majority identified risk factors such as obesity (80.7%), but not older age (64.7%), diabetes (68.6%), and being male (87.4%); 34.9% did not know whether cardiac disease is curable. 30% heard of CR and were optimistic about it. 81.7% used Western medicine more than TCM. 47.7% and 44% perceived Western medicine or a mixture of both medicines more effective than TCM alone. 56.2% of participants aged >50 saw Western medicine as the best treatment, younger participants saw a mixture of both medicines as better.

Legend: TCM traditional Chinese medicine, CR Cardiac rehabilitation

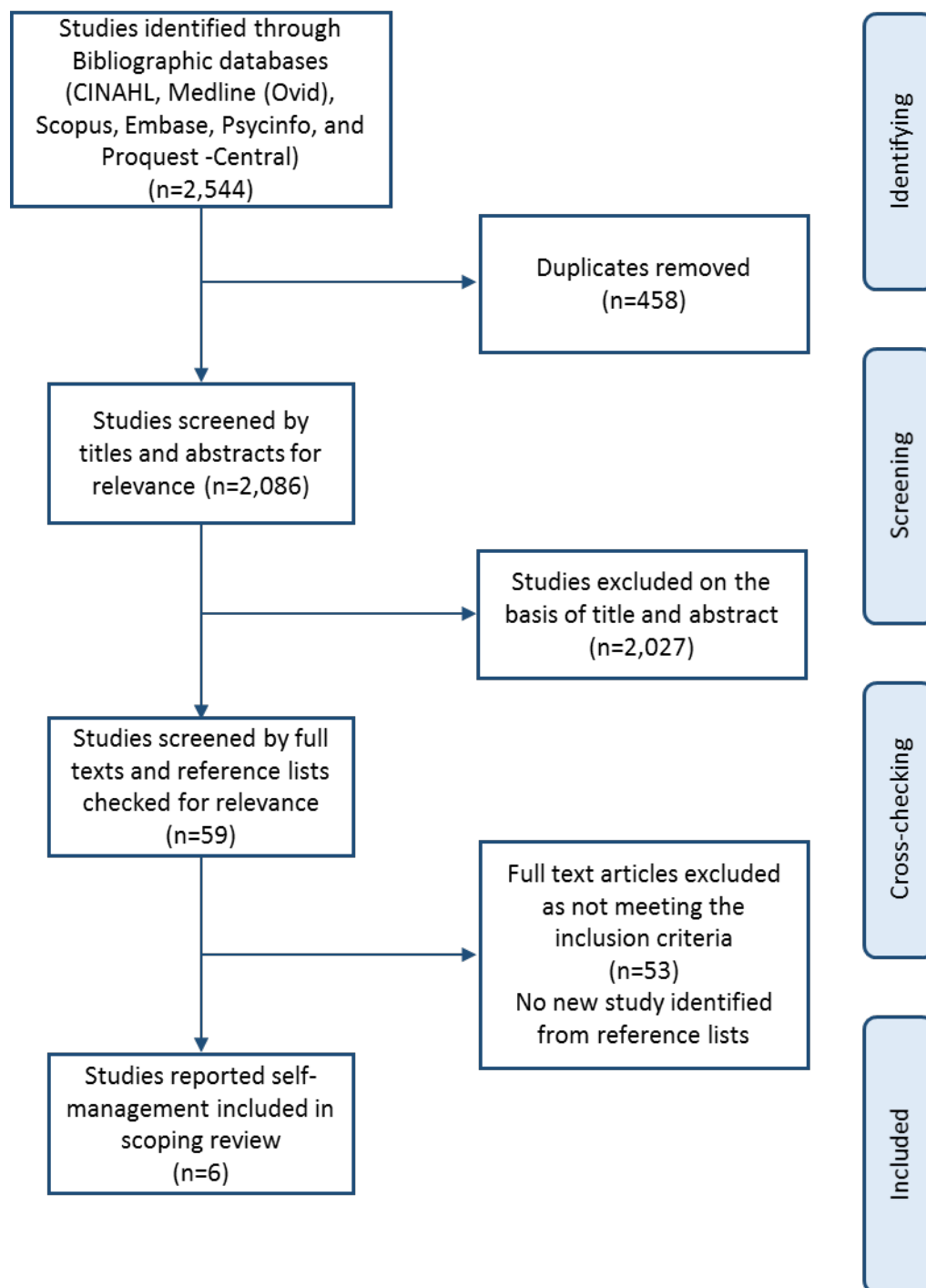


Figure 1. Literature search flow diagram