

Experience and perspectives on palliative or end-of-life care of Chinese people and their families as immigrants to high-income countries: a systematic review and thematic synthesis

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ABSTRACT

Background A sizeable cohort of Chinese migrants in high-income non-Asian countries is reaching old age and many will develop life-limiting illnesses. They may benefit from palliative care, which is integrated into universal health coverage in many of these countries, but the uptake of this care among migrant communities remains low. Cultural differences between the Chinese and the host community, and poor language skills may be barriers to access, yet understanding the reasons hindering uptake are obscure.

Aims To understand the cultural perspective of how first generation Chinese migrants and their families perceive the provision of palliative care, to identify what exists which may limit their access in high-income non-Asian countries.

Design A systematic review and three-stage thematic synthesis of qualitative studies. Citations and full texts were reviewed against predefined inclusion criteria. All included studies were appraised for quality.

Data source MEDLINE, EMBASE, PsycINFO, CINAHL and PubMed were searched to July 2019.

Results Seven qualitative studies were identified (from USA, UK, Canada and Australia). Across the studies analytical themes that impacted on the use of palliative care services were identified: (1) migrants' intrinsic perceptions of cultural practices, (2) their expectations of and preparation for care at the end of life, (3) perspectives and influences of family and (4) knowledge and communication with palliative care providers in the host country. Key elements found that challenge access to palliative care services in the host countries were: Chinese culture is rooted in the core values of the family as opposed to the individual; migrants' limited experience in their place of origin in accessing healthcare; and practical issues including a lack of language skills of their host country.

Conclusions Palliative care services do not always match the needs of Chinese migrants in non-Asian high-income countries. Engagement and education on multiethnic cultural awareness in both the host non-migrant and the migrant communities is needed.

Key questions

What is already known?

- The use of palliative care services among migrants is less than that of many host populations in high-income countries.
- In traditional Chinese culture death is a taboo which should be avoided when talking with senior family members.

What are the new findings?

- Traditional Chinese medicine may be preferred or taken alongside medical treatments for pain and other symptoms
- The family is central to making key decisions about family members welfare. Death taboo and filial piety can delay direct communication about advanced care planning.
- First generation migrants may lack an understanding of what palliative care is, some may not adequately speak the host countries native language and provision of healthcare translation may be inadequate.

What do the new findings imply?

- The lack of engagement of Chinese migrants in palliative care goes beyond a language barrier. To enhance uptake, the findings suggest the need to further acknowledge the cultural perspectives of migrants including the importance of involvement of the family.

INTRODUCTION

Palliative care, encompassing end-of-life care, is an approach that aims to provide optimal quality of life to people with life-limiting incurable diseases and their families.^{1 2} It achieves this through the early identification of suffering, and the assessment and treatment of physical, social, psychological and spiritual needs. Such care can be provided through hospice care in dedicated facilities or at home. The importance of palliative care is

recognised with its inclusion in the United Nations' International Covenant on Economic, Social and Cultural Rights in 2000 and it has now become integrated into universal health coverage in the health systems in many countries.³ The provision of palliative care services is well established in high-income countries, where advanced hospice-palliative care is often integrated into mainstream healthcare service provision.^{4,5} The global coverage and payment of such services varies by country,⁴ which in turn influences the health-seeking behaviour of people at a palliative stage of a disease. There are also inequalities in access within countries beyond any regional differences, this includes certain population groups.⁶ One such group are ethnic minorities, other groups include those living in more deprived areas or who are socially isolated.

There are policy and organisational initiatives that aim to reduce disparities in accessing palliative care including in the USA,⁷ in Scotland⁸ and across the UK.⁹ Some strategies that aim to be culturally competent for ethnic minority needs have been integrated into countries' health systems. This includes provision of education for healthcare providers on the unique customs of minority populations, and development and application of skills aimed at embedding race-equality strategy. These may involve education on the appropriate codes of behaviour towards ethnic diversity, and ensuring that all organisational procedures and decisions are clear and equitably applied within the context of a diverse patient population.¹⁰ Although findings from the USA have suggested that these strategies have had limited impact in the uptake of palliative care services among migrant communities.¹¹ Other recent initiatives have recommended the need to gather more on the experiences and needs of population groups that access less palliative care.⁹

To better understand the engagement and uptake of palliative care by migrant populations, it is helpful to look at trends in global migration since the Second World War, which saw population shifts from lower-income countries to higher-income ones. The Chinese diaspora community refers to Chinese living outside China, Hong Kong, Taiwan and Macau. They are a good example illustrating these shifts, where major changes to the immigration policies of high-income non-Asian countries, particularly in Anglophone countries such as the USA, Canada, the UK and Australia from the mid-1960s onwards,¹² have seen increases of ethnic Chinese migration. Chinese migrants now make up a sizeable proportion of the population of the USA, Canada and Australia.^{13–15} For example, in the USA since 1980, there has been a sixfold increase Chinese immigrants and who in 2018 totalled over 2.4 million people. Currently, in Australia, this group makes up 8.9% of the foreign-born population.

Many of the Chinese who migrated at working age in the mid to late 20th century will now be reaching older age. This older group of migrants are now at an increasing risk of developing advanced life-limiting illness (malignant and non-malignant), leading to physical,

psychological and social needs, which may benefit from a palliative care approach. Chinese migrants generally like other minority groups have greater difficulty in accessing health services in their host country^{16,17} and are less likely like other minority groups to receive formal palliative care services than host populations, despite the general availability of these services in these high-income Anglophone countries. Several factors are likely to account for the lack of uptake of healthcare services by the Chinese migrant population. One, cultural differences between the Chinese and the host community. The traditional values held by some of the Chinese migrants, such as filial piety and collective well-being of families can be seen to contradict the culture of high-income Anglophone countries, with its greater emphasis on individualism and a de-emphasis on extended kinship relationships.¹⁸ Thereby when approaching death migrants may understandably have a preference for adopting Chinese practices than those of the host country.^{19,20} Another factor is their experiences of healthcare in their country of origin. China's health system, for example, especially before the reform introduced in 2009, was one of the typical healthcare structure in developing countries which required a large proportion of out-of-pocket payment, and lacked social health security or insurance coverage. The unaffordability of healthcare in turn limited its access among both urban and rural residents of China.^{21,22} Another factor limiting Chinese migrants' interaction with host healthcare service may be poor English language skills, as unlike subsequent generations, those now reaching older age are likely to have received a more limited education.²³

There are known qualitative studies that have explored Chinese migrants to high-income countries in relation to end-of-life and palliative care. To identify how to potentially improve access to provision of palliative care and what barriers exist preventing Chinese migrants from accessing this care, this systematic review, through a thematic synthesis of qualitative studies, builds on these studies to seek a more in-depth understanding of the cultural perspective to how Chinese migrants and their families perceive and experience the provision of palliative care.

METHODOLOGY

Review framework including patient and public involvement

In this systematic review, we followed recommended approaches and tools as appropriate to our research question. We did not involve patients and public in the research process.

Identifying studies for review

We included qualitative studies on the perspectives of Chinese migrants who either received palliative care or were family caregivers if they met all the criteria in [box 1](#).

Search strategy and selection criteria

Database searches were conducted from inception to 22nd July 2019 in MEDLINE (OVID), EMBASE (OVID),

Box 1 Study inclusion criteria

Inclusion Criteria

1. Study design

Qualitative study, defined as:

 1. Data collection using in-depth or semistructured interviews and/or focus group discussions.
 2. Data analysis method being qualitative.
2. Study population and aim

Participants were first generation Chinese migrants who either received palliative care or were family caregivers and for which their perspectives were sought.
3. Data
 1. There were extractable data on Chinese migrants' perceptions of receiving palliative care either in general or in specific services, for example, what do they know about the end-of-life care, or how do they perceive the healthcare workers providing them the service. If the study included Chinese migrants and participants from other ethnic groups, only data on Chinese migrants were extracted.
4. Palliative care

The topic for which the participant's views were sought was palliative care. This included pain management, end-of-life discussions or advanced care planning in all settings, for example, hospice or home care, and regardless of patients' age and medical condition.
5. Reporting language

Only papers written in English were included.
6. Report format

Only empirical studies published in peer-reviewed journals were included. Dissertations, thesis and conference abstracts were not included.

PsycINFO (OVID), CINAHL (EBSCO) and PubMed. Full search terms and strategy are detailed in online supplemental appendix A. The reference lists of relevant papers were examined to ensure all relevant studies were included. Screening of titles and abstracts was undertaken by one author (HHYK) with a sample checked by other authors to ensure consistency. All authors agreed those to be included at full text.

Quality assessment

The Hawker quality assessment tool²⁴ was used to examine the methodological rigour of the reviewed articles. Nine items were assessed and scored by a four-point Likert scale, ranging from 1 (equivalent to 'very poor') to 4 (equivalent to 'good'). These items related to the abstract, introduction, methods, sampling, data analysis, ethics, results, transferability and implications. To ensure the comprehensiveness of information, all studies, regardless of their quality, were included in the synthesis. We did explore if the level of quality studies contributed to our themes in a different way. If this was found and appeared to impact on the results, we took this into account in our conclusions.

Thematic synthesis

We followed a three-stage method for thematic synthesis: (1) categorising the text segments based on their meaning (the line-by-line coding of text); (2) developing

descriptive themes by grouping similar codes with meanings and (3) generating analytical themes (overarching themes) by considering the descriptive themes in relation to an operational framework depicting how the participants perceive and receive palliative care.²⁵ First, the direct quotes and their corresponding line-by-line codes were presented in a table in a Microsoft Word document, followed by deriving higher-level free codes from the initial codes (see online supplemental appendix B). Second, all free codes were put in a Microsoft Excel file for grouping according to their meanings. Descriptive themes were generated by the similarities among the free codes. Third, the descriptive themes were rephrased or summarised in clearer terms to generate analytical themes (overarching themes) according to the objectives of this review. One reviewer generated this (HHYK) and the second checked it (BC).

RESULTS

The search strategy identified 369 citations. At screening 35 studies were potentially relevant. At full-text assessment seven studies were included.^{26–32} The reasons for exclusion are shown in figure 1.

Table 1 describes key characteristics of the included studies. Four studies were conducted in the USA^{29–32} with the remaining in the UK,²⁶ Australia²⁷ and Canada.²⁸ Purposive sampling or snowball sampling were mainly used in the studies and data were collected through interviews or focus group discussions. Grounded theory and interpretive thematic analysis were adopted as analytical methods. Apart from one study²⁸ which was a focused ethnography. Perceptions and feelings in receiving palliative care, as well as barriers of deterring people from accessing palliative care were explored in all studies.

Participants

Overall the views of 82 recipients of palliative care (patients), 23 family carers (all adult children), and 21 healthcare providers were presented in the studies (table 1). In Fang *et al*²⁶ and Mondia *et al*,²⁹ these were those of Chinese migrants aged under 55 years. Yonashiro-Cho *et al*³⁰ recruited mainly elder Chinese, while Chi *et al*³¹ and Nielsen *et al*²⁸ recruited adult children and healthcare providers. Heidenreich *et al*²⁷ explored the views of family carers aged between 55 and 65 years. The perspectives of only female migrants, were explored in studies of Fang *et al*,²⁶ Heidenreich *et al*²⁷ and Mondia *et al*²⁹

Quality appraisal

Table 2 presents study quality assessment,²⁴ which showed variable quality across the studies. Of the seven studies, Fang *et al*²⁶ was of highest quality, its findings contributed (because of relevance) the most to the data synthesis in this paper.

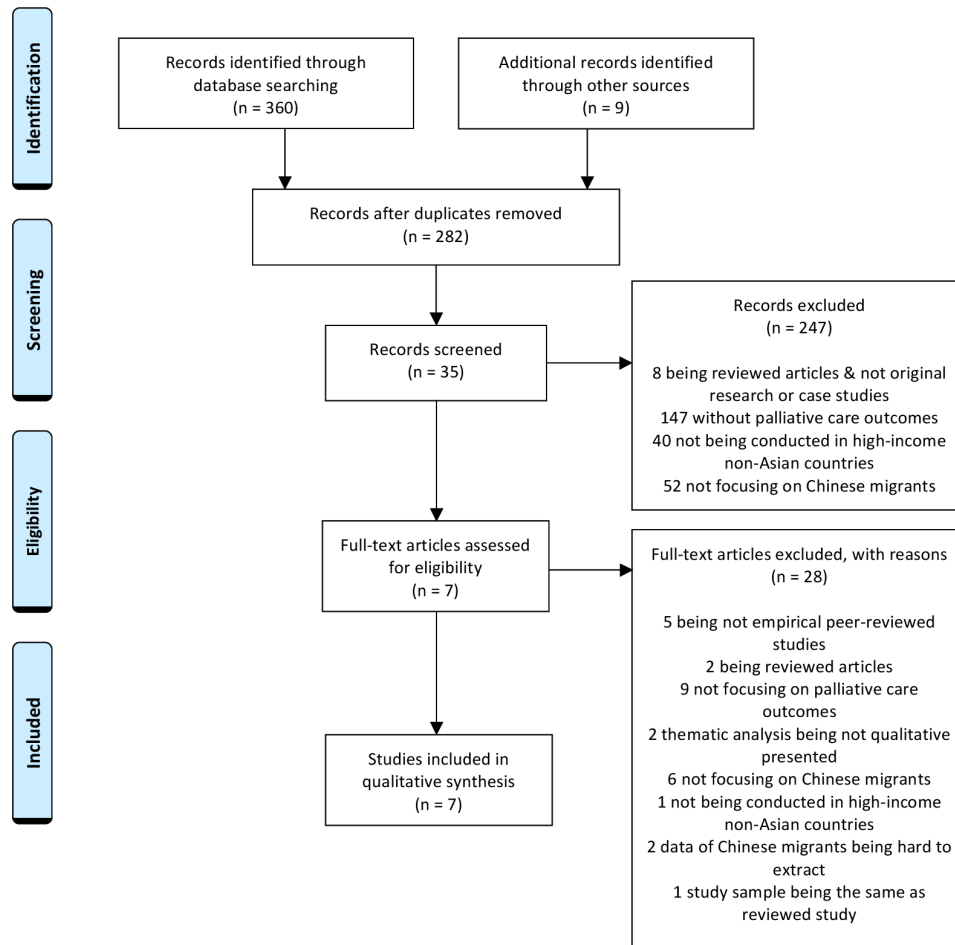


Figure 1 PRISMA flow diagram of primary studies. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

Results of data synthesis

The four overarching themes that emerged from our data synthesis were: (1) intrinsic perceptions of cultural practices, (2) patient expectations on care at the end of life, (3) perspectives and influences on family carers and (4) knowledge and communication in regard to palliative care provision in the host country. We found subthemes within these groups that highlight both differences that Chinese patients and their families may have in general with those in the host country (e.g., the concept of filial piety) but also end-of-life issues that may be similar irrespective of cultural background (e.g., not wanting to burden others).

Table 3 outlines the main themes and their corresponding subthemes. The thematic analysis process is documented in online supplemental appendix B.

Intrinsic perceptions of cultural practices

This theme reflected the participants (mainly the recipients of care) understanding of their traditional cultural beliefs and how it may affect their perceptions on palliative care in their host country. This was found in four studies.^{26–28 32} Recipients described being conflicted by the social norms of the host country that pertain to end-of-life care including the differing roles and expectations

of family and healthcare providers, and in care management.^{26 32} They talked about a sense of obligation to follow host country’s cultural expectations. Moreover, as perceived ‘newcomers’, migrants needed to engage in society outside the Chinese circle,²⁶ as they were geographically and socially detached from their original family and community support systems in their place of origin.²⁷ Some preferred worshipping Chinese gods, but felt pressured to accept new religious images relevant to the host culture.²⁶ A mix of traditional Chinese and current treatments were used by some (Nielsen *et al*²⁸), despite the integration of traditional Chinese medicine alongside current mainstream treatment being discouraged by healthcare providers.^{28 32} Some described these challenges as ‘dampening’ their mental well-being.

Another common thread in these studies was that as Chinese migrants they saw dying as a private matter, and that additional support beyond the family was not important.

Having your family take care of you is better than having the government do it.—Chinese woman living in England²⁶

Participants believed that as death is natural and inevitable,²⁶ treatments were not needed, in particular taking high doses of medications.³² There was reluctance

Table 1 Characteristics of studies included in review

Author	Title	Aim(s)	Setting	N	Participants	Data collection method	Analytical approach
Fang ²⁶	Exploring traditional end-of-life beliefs, values, expectations, and practices among Chinese women living in England: Informing culturally safe care	To explore the end-of-life beliefs, values, practices, and expectations of a select group of hard-to-reach Chinese women living in England	England, UK	11	Marginalised Chinese women aged 25–54	Individual in-depth semistructured interviews	Grounded theory
Heidenreich ²⁷	The experience of Chinese immigrant women in caring for a terminally ill family member in Australia	To explore the influence of Chinese cultural norms and immigration on the experience of immigrant women of Chinese ancestry caring for a terminally ill family member at home in Sydney; To identify factors that may present access barriers to palliative care support services	Sydney, Australia	5	Asian women carers of Chinese ancestry reside in Sydney, aged 55–65	Semi-structured face-to-face in-depth interviews	Interpretive thematic analysis
Nielsen ²⁸	Patient-centred care or cultural competence: Negotiating palliative care at home for Chinese Canadian immigrants	To deepen thinking and understanding of Chinese immigrant experiences of palliative home care	Ontario, Canada	23	11 key informants four first generation Chinese immigrants, aged 50–80 five family care givers three home visiting nurses	Focused ethnographic study; in-depth open-ended individual interviews	Postcolonial theory
Mondia ²⁹	The impact of Asian American value systems on palliative care: Illustrative cases from the family-focused grief therapy trial	To examine the challenges and opportunities that arise in family work and examine the cultural underpinnings that impact on outcomes	USA	5	Chinese American family (care recipient, her brother, elder sister, two nieces)	Qualitative analysis of 36 therapy sessions	not stated

Continued

Table 1 Continued

Author	Title	Aim(s)	Setting	N	Participants	Data collection method	Analytical approach
Yonashiro-Cho ³⁰	Knowledge about and perceptions of advance care planning and communication of Chinese-American older adults	To explore the knowledge, attitudes, and preferences of older Chinese Americans toward advance care planning	USA	34	Chinese-American older adults residing in urban areas	Focus groups	Grounded theory
Chi ³¹	Please ask gently: using culturally targeted communication strategies to initiate end-of-life care discussions with older Chinese Americans	To explore communication strategies for Health care providers (HCPs) to initiate end of life care discussions with older Chinese Americans in the San Francisco Bay Area	San Francisco Bay Area, USA	30	14 community-dwelling older Chinese Americans nine adult children 7 HCPs	Qualitative (focused) ethnographic study; Field observations; Individual semistructured interviews	Constant comparative analysis
Duke ³²	Perspectives of Asians living in Texas on pain management in the last days of life	To determine the attitudes about and preferences for pain management in the last days of life for persons born in Japan, China and Vietnam living in	Texas, USA	18	Chinese residing in Texas, aged 29–82	Descriptive qualitative study; a combination of individual and small focus group interviews	Thematic analysis

Table 2 Quality appraisal scores (using tool from Hawker *et al*²⁴)

Source paper (n=7)	Abstract/title	Introduction/ aims	Method/data	Sampling	Data analysis	Ethics/bias	Results	Transferability	Implications	Score (out of 36)
Fang <i>et al</i> ²⁶	4—Structured abstract with full information title is clear	4—concise background to discussion, contain up-to-date literature review, highlight gaps in knowledge; statement of aim and objectives may not be clear but can still be found in the paragraphs	4—method is appropriate and described clearly (interview themes mentioned); clear details of the data collection and recording	4—appropriate sampling method; details of who was studied and how they were recruited; explained the reason of being targeted; response rate and justification of sample size are not mentioned in the study	4—clear description of how analysis was done; detailed description of how themes derived	4—ethics: address issues of confidentiality, sensitivity and consent; bias: researcher was reflexive and aware of own bias	4—findings are explicit and easy to understand as the authors divided them into different paragraphs per different themes; tables are explained in text; results directly related to aims	3—only insights of young and marginalised women affected generalisability	4—provided insights from a gender lens, letting us to see whether women being treated unequally; suggest ideas for further research and implications for policy and practice	35
Heidenreich <i>et al</i> ²⁷	4—structured abstract bit better to divide in sections	3—clear statement of aims but no objectives	4—appropriate and described in detail; included interview questions; clear details of the data collection and recording	4—inclusion criteria listed and sampling method appropriate; how study population being recruited described clearly; justified why target this group of participants	4—clear description on how analysis was done; how themes derived are described	3—researchers' own bias not acknowledged	4—findings easy to understand, tables are easily read and explained in text; results relate to aims	3—some context and settings are described but replication of study with larger sample size and different sites are needed	4—contribute to something new; discussed the research question (communication); suggestions of ideas for further research and implications for nursing practice	33
Nielsen <i>et al</i> ²⁸	3—abstract not in good structure	3—full background for explaining the framework used in the study but little mention in the knowledge gap; literature review and background is adequate but aims and research questions not clear	1—no details of data collection	3—inadequate information of sampling strategy	1—no details of data analysis	2—no mention of bias acknowledged	4—findings were easy to follow and understand in a logical progression with subheadings; results directly related to purpose of the study	3—context and setting of the study is described	3—new insights mentioned; suggested ways for policy change	23
Mondia <i>et al</i> ²⁹	3—abstract with most of the information; purpose was not stated	3—inadequate background and literature review; aim and objectives are mentioned; research gap is acknowledged	3—method can be described in details	2—no mention of sampling method or settings	2—inadequate details of data analysis	2—only one sentence for de-identification	3—presented logically but more can be added to illustrate results	2—only some context and setting described	3—further research direction and clinical implications are mentioned	23

Continued

Table 2 Continued

Source paper (n=7)	Abstract/title	Introduction/aims	Method/data	Sampling	Data analysis	Ethics/bias	Results	Transferability	Implications	Score (out of 36)
Yonashiro-Cho <i>et al</i> ³⁰	3—abstract with most information but not well-structured	3—some background to discussion, highlighting in knowledge gaps; clear statements of aim and objectives; no research question mentioned	3—method appropriate and data collection is given; recruitment mentioned but can be further elaborated in detail; focus group protocol is included	3—appropriate sampling method; recruitment can be given in detail	3—described grounded theory used and theme derived from coding; more can be given	1—no mention of issues of confidentiality, sensitivity or consent	3—findings in logical progression but can be elaborated more; demographic table was explained in text; data presented relate directly to results	Three context and settings of immigrants in America was described but the interpretation of results may not be generalisable	4—good to suggest informal and indirect ways for communication	26
Chi <i>et al</i> ³¹	4—structured abstract; good literature review	3—concise background to discussion; highlighted the knowledge gap; clear statement of aim but no objectives mentioned	4—appropriate focused ethnographic study with justification; data collection is described with sample interview questions; handling of data is described with information	3—sampling method is appropriate; inclusion criteria recruitment process described; why this group is targeted is missing	4—clear description of how analysis was done; description of how theme derived using open coding and there was triangulation to strengthen the study's rigour	2—only mention informed consent given	4—incldings are explicit and easy to understand; shown clearly in tables; results related directly to aims; direct quotes were presented to support findings	3—context and settings were given and described	4—new insights demonstrated; suggested ideas for further research; suggested implications for practice	31
Duke and Petersen ³²	4—structured abstract with aim, method, results and conclusion; clear title is given	3—no mention of objectives	4—method is appropriate and described clearly; details of data collection clearly shown	4—inclusion and exclusion criteria of participants described; how they recruited was stated; why this group being targeted mentioned; sample size has not justified but response rate is shown yet without explanation	4—clear description of how themes derived: using Krippendorff's thematic data analysis method	3—informed consent was address but confidentiality and sensitivity were not acknowledged; researcher bias was addressed through training for them	4—findings explicit to understand; four themes were discussed point by point; table with themes and subthemes was elaborated in text; results related directly to aims; direct quotes from interviews and focus group discussions used to support the findings	3—most context and setting described, data collected through the study subjects were not generalisable	3—new insights that there should not be cultural stereotype and assumption based on ethnicity or culture group; suggests implications for practice	32

Table 3 Themes, subthemes and included reviewed articles

Themes	Subthemes	Papers included
Intrinsic Perceptions of Cultural Practices	Cultural background and practices Gender role in care	Fang <i>et al</i> ²⁶ Heidenreich <i>et al</i> ²⁷ Nielsen <i>et al</i> ²⁸ Duke and Petersen ³²
Expectations and Comments of Patients on care at the end of life	Personal expectations Healthcare service provision Self-recognition and concerns Appropriate timing	Fang <i>et al</i> ²⁶ Heidenreich <i>et al</i> ²⁷ Nielsen <i>et al</i> ²⁸ Mondia <i>et al</i> ²⁹ Yonashiro-Cho <i>et al</i> ³⁰ Chi <i>et al</i> ³¹ Duke and Petersen ³²
Perspectives and Influences on Family Carers	Considerations of caregivers Caregivers' health Barriers in care engagement	Heidenreich <i>et al</i> ²⁷ Nielsen <i>et al</i> ²⁸ Mondia <i>et al</i> ²⁹ Yonashiro-Cho <i>et al</i> ³⁰ Chi <i>et al</i> ³¹ Duke and Petersen ³²
Knowledge and Communication in regards to palliative care in host country	Knowledge of end of life care Communication and relationship	Fang <i>et al</i> ²⁶ Nielsen <i>et al</i> ²⁸ Yonashiro-Cho <i>et al</i> ³⁰ Chi <i>et al</i> ³¹ Duke and Petersen ³²

to involve healthcare providers for fear of treatment side effects and that they may lose their autonomy,^{26 27} although for some, this reluctance was based on previous negative experiences of using healthcare services in their place of origin.³²

While participants had an expectation of their families providing care for them, this was not straightforward. Some saw problems about by being cared for at home, with one participant stating a superstitious belief that if you die at home, your home cannot be resold, while for others it was a fear of burdening their family.²⁸

Care recipients' expectations of and preparation for care at the end of life

This theme on perceived care at the end of life was seen in all studies.

Participants had strong beliefs about the importance of family values, and that care decisions were often made collectively or deferred to the family.²⁷ Some participants highlighted the loss of these values in their children as second generation citizens of the host country.²⁷

Participants seldom expressed the need to discuss advanced care plans (end-of-life care discussions) and only did if they had managed to accomplish all their wishes with their family^{31 32} or when they felt that they

were in their late stages of life.^{26 30 32} Moreover, they would not actively initiate end-of-life care discussion with their family even when the pain exceeded their tolerance level.^{30 32}

Towards the end of my mum's life, my mum would like to discuss [end of life care preferences] ...—Chinese person living in USA³⁰

Some senior family members expected their children to be the primary caregivers,²⁶ but at the same time, these senior family members would also avoid imposing on their family when they were dying.^{28 32} Likewise, patients did not want to appear troublesome to their healthcare professionals and went out of their way to please them.^{27 29 32}

... please the doctor or nurse ... [and desires] to be easy to deal with, I'm not a trouble maker ...—Chinese person living in USA³²

Some participants anticipated that to provide culturally appropriate care, healthcare providers would need to be sensitive about the 'taboo' surrounding the discussion of death and respect other nuances of Chinese customs such as incense or paper money burning in relation to Taoist belief.^{26 31}

any time you're dealing with an older Chinese, ask them "Are you superstitious about talking about preparing for death?"—Chinese person living in USA³¹

In two studies participants found that the culturally sensitive service was substandard in the availability of interpretation services and ineffective in the self-translation by using electronic dictionary. This contributed to the underutilisation of services.^{26 30}

Perspectives and influences on family carers

This theme looks at the views and concerns of family carers towards palliative care.^{27–32} Carers were found to be reluctant in seeking external assistance and preferred not to disclose the terminal nature of illness to their sick family members.²⁷ If end-of-life discussions with the patient and their family were seen as necessary, some insisted they should be initiated by the healthcare providers.^{30 31} Children initiating end-of-life discussion was perceived as cursing their parents to die, which in other words was unfilial.³⁰

It's better for the parents to bring it up first. Otherwise, the children might worry that ... their parents will feel like the children are trying to curse that they are dying—Chinese woman living in USA³⁰

While adult children may care for parents out of familial bonding and individual feelings of responsibility,^{26 27} some may be unable or unwilling to.

if we are living in our own culture there is always the case for children to be looking after their parents. So normally they would stay home together with their children. But here because of the Western influence they become

independent and they move out and they don't want to live with their parents.—Chinese woman living in Australia²⁷

Knowledge and communication in regard to palliative care in host country

Five studies^{26 28 30–32} explored the ways in which the knowledge of services and treatments such as pain management, and the timing of end-of-life discussion, impacted on the experiences of migrants. In general, both patients and family carers had limited knowledge of palliative care practice in their host country.^{26 28 32} For many, palliative care services did not exist in their place of origin (China, Hong Kong and Taiwan) or at least at the time they left to move to their host country. This in turn limited their understanding of what palliative care may be in the host country, and so had an impact of their demand and uptake for this type of care.²⁸

I don't think they 100% understand what is palliative care for them...In China or in Hong Kong we don't have home care.—a home care nurse from Hong Kong²⁸

Some migrants feared a loss of cognitive functioning out of addiction or overdose to medications which may be offered as part of pain relief. This in turn decreased participants' acceptance of this service.³²

Participants who could not express themselves well in English found it hard to communicate and negotiate with the healthcare professionals.²⁸ Some suspected their doctors discriminated against them due to their limited English language skills.²⁶

If the doctor is impatient, he doesn't want to spend a lot of time listening to us. Because we are limited in the English language ...—Chinese woman living in England²⁶

English-speaking migrants had less misunderstanding and were more familiar with the palliative care service than the non-English-speaking individuals.³⁰ However, even those confident in speaking English were still reluctant to engage with palliative care.³⁰ Many preferred speaking in their dialects when using health services.²⁶ Though healthcare providers attempted to match their patients with staff by ethnicity, they were not aware of the importance of dialect matching.²⁸ In adopting a culturally targeted communication approach to encourage migrant to use palliative care, participants felt that healthcare providers needed to have good understanding of Chinese cultural complexity.^{26 31} They needed to ensure that when discussing end-of-life issues with participants to consider engaging in indirect communication, where these conversations do not directly discuss the participants' own health deterioration, but brooch these topics in general terms.³¹ Participants felt that the use of these strategies would lower the stress levels of Chinese recipients of palliative care.^{30,31}

DISCUSSION

This thematic synthesis of seven qualitative studies captured the experiences and perceptions on palliative

and end-of-life care of Chinese who had migrated to high-income non-Asian Anglophone countries. Most respondents were either recipients of palliative care or family members involved in caring for someone using palliative care services. The synthesis identified four overarching themes which may limit palliative care access to Chinese migrants in their host country: (1) their intrinsic perceptions of traditional cultural practices, (2) participants' own expectations about end-of-life care, (3) the perspectives and influences of family carers and (4) participants' knowledge about palliative care provision in the host country. Each theme was represented in data in more than half of the included studies, thereby demonstrating a commonality of findings across the body of work. Overall the synthesis identified three key elements from these themes. One, Chinese cultural ideology and the stronghold of traditional practices. Two, the limited experience of these migrants in accessing healthcare in their place of origin before migrating overseas. Three, practical issues such as a lack of language skills of their host country, which limited their communication with healthcare professionals. For some Chinese migrants these elements limited their use of host healthcare system including to access palliative care.

We found that some recipients of palliative care had a deep-rooted Chinese cultural ideology which is different from the host culture. Chinese culture is strongly influenced by Confucianism and Taoism, where death is natural and inevitable but associated with fear and mystery. It is not regarded as another phase of life in the way that many Christians believe.³³ The family is the fundamental social unit throughout Chinese history. Thereby the goal of advanced care planning as a means to facilitate patient autonomy is at odds with Chinese traditional culture, where individual autonomy is subordinate to other authorities including family values.^{19 34} A Chinese saying goes, 'Rear sons for help in old age; and store up grains against famine'. This notion encourages people to raise children and provides old people a sense of security. Together with filial piety, traditionally Chinese people are encouraged to be responsible for taking care of their parents when they grow up. In contrast, the dominant culture in many high-income countries, in particular Anglophone, promotes individualism, with children moving away from the family when they grow up. This strong sense of collectivism, unity and togetherness within Chinese families illustrates Chinese migrants' preferences of receiving support and care from their family, and making decisions collectively as opposed to relying on healthcare providers.

Our findings illustrate that the reluctance of Chinese migrants both to seek help from healthcare providers and their sometimes negative feelings for palliative care provision in their host country may also partly stem from their own past experience of healthcare in their place of birth and the differences between this and the care provided in their host country. Access and affordability to mainland China's healthcare system has been poor

especially prior to the 2009 healthcare system reform, in which a large proportion of the population had no financial health protection and were required to make high out-of-pocket payments for healthcare.³⁵ For example, in 2003, 45% and 79% of urban and rural populations, respectively, were not covered by social health insurance schemes.³⁶ In Hong Kong, there are also issues in access and affordability. The public healthcare sector has been overburdened for decades by its high usage rate with low user charges, leading to long waiting lists for many healthcare services.³⁷ This unresolved issue has pushed the Hong Kong government to advocate public-private partnership and encourage citizens to get private health insurance.³⁸ However, the uptake of insurance has been found to be limited.³⁹ Thereby, Chinese migrants have been accustomed to relying on family for support due to inadequate public healthcare financial support. This contrasts with host countries where the local population is used to accessing public health system including free access to palliative care. Although this is not the case everywhere, in the US palliative provision is funded by Medicare and private insurance plans.

For many Chinese migrants, there may be a misunderstanding of what palliative care in their host countries offer, in particularly pain control, which many believe would lead to opioid addiction.³² This may in part have a historic link to the Opium Wars between Britain and China in the 19th century and associated wide-spread addiction, but also because they may feel that their preference for traditional Chinese medicine would be discouraged by healthcare providers in their host countries. Although some second-generation Chinese were less willing to conform to traditional Chinese cultural expectations, others who were family caregivers were reluctant to seek help from the health system. They preferred to do all aspects of care themselves. This may be as they perceive that doctors were not competent in placing their own interests above those of the patients when making decisions,³⁹ in contrast to family members who are better able to make judgements according to the patients' best-interest judgements. However, there may also be pragmatic reasons for family members continuing to care for their relatives such as the loss of family money if the relative went into a nursing home.

Chinese migrants had limited knowledge of palliative care or its potential benefits, though this lack of knowledge may also apply to some members of host populations, in particular those who have not experienced friends or family receiving such care. One difficulty migrants have is poor English language skills which limits the ability of healthcare providers to engage with this patient group about the services that palliative care can offer. In the USA, the UK, Australia and Canada, there are policies and guidelines on translation and interpretation service that aim to help ensure people are able to get access to healthcare service regardless of their languages, despite the different health systems. Although previous studies have shown an underuse of professional interpreters

in the USA and Australia, for example,^{40 41} we are not aware of research showing if the provision of interpreters meet the demands of Chinese migrants. Our review identified that participants preferred to use their own dialects/languages in accessing healthcare, suggesting that it is equally important for healthcare providers not to treat the Chinese migrant community as a homogeneous group. Although, language ability alone is not the only issues to consider as even Chinese migrants with good English language skills were reluctant to use palliative care services, again emphasising the importance of cultural factors.

Chinese migrants can benefit from palliative care service as much as other populations; the key difference lies in their medical help-seeking behaviours. Fogg behaviour model⁴² suggests that people are able to have their behaviour changed only when they are motivated enough and have the capability to perform the desired behaviour. In our review of literature, Chinese migrants at a palliative stage of a disease and their families were not always motivated to seek help from professional healthcare workers because of various hindering factors which we found were mainly rooted in cultural differences. Without recognising the importance of these barriers, the successful promotion of palliative care in the form of professional care will be limited.

Strengths and limitations

We believe this is the first systematic review specifically in this area. It used rigorous and transparent methods in assessing study quality and in analysis of data. Resource limitations, however, prevented us involving patient and public in the research project. Their input would have been particularly informative in the thematic synthesis. However, the themes that emerged were well represented across the studies which were all published relatively recently and represented the voices of over 100 patients and their families. Overall, the methodology used in the papers reviewed were appropriate. All the included studies came from high-income Anglophone countries, mainly the USA and Canada. These two countries represent two forms of healthcare, which may not be generalisable to other countries. Our sample was predominantly female as three of the reviewed articles^{26 27 29} targeted only female Chinese migrants in part perhaps as they are more likely to be their parents' caregivers.⁴³ Nevertheless, we found that their perceptions on palliative care were consistently similar to male participants. Our participant sample comprised participants speaking various dialects, and came from mainland China, Hong Kong and Taiwan. We assumed that this represented the Chinese diaspora community, but acknowledge that we were unable to separate according to the place of origin, a factor which may be important in affecting participants' experience in accessing both health and palliative care. Another consideration is that our findings focused on limitations preventing migrants accessing palliative care. The barriers we found are not relevant to all migrants as

many may not follow traditional culture, they may lack religious beliefs and have a very open attitude towards life and death issues. They may have also enjoyed better medical treatment in their country of origin than is available in their host country and have not migrated for economic reasons.

Implications for practice

Cultural beliefs of Chinese migrants were highlighted as a key barrier to palliative care services in this population. While it is beyond the scope of this review to recommend certain policy or practice initiatives that may increase uptake, we can suggest a few potential strategies in developing more culturally sensitive services.

One is the recruitment of language-competent healthcare professionals, ideally first generation ethnic Chinese migrants, who would be available to match with the migrant population in terms of dialects/languages. Additional staff in the form of qualified translators working in healthcare would be needed and could be used to support palliative care professionals in this context, provided they were given appropriate training in palliative care for this role. It would be important to monitor these language assistance services for uptake and effectiveness. A second strategy is training healthcare providers on how to communicate effectively with the Chinese community when talking about palliative care. Healthcare providers need to be aware that a more nuance and indirect approach may be required when discussing issues related to health deterioration and death to Chinese migrants. It is important to recognise the traditional taboo on talking about death. Some families may be reluctant and uncomfortable to initiate a conversation about end-of-life discussions with a sick relative and would prefer this to be done by health professionals. In communicating with patients and their families, health professionals could consider substituting the term 'palliative' or 'end-of-life care' with other wordings like 'comfort treatment'.⁴¹

Our findings highlight that Chinese participants often rely on family members to provide their care. In turn, family members are reluctant to use palliative care services, although they may prefer healthcare providers to discuss disease progression and end-of-life wishes with the patients. Healthcare providers should aim to establish an early working relationship with family members of patients, to gain their trust and explore ways in which they can discuss sensitive issues of disease progression with the patients. We found Chinese migrants are unclear about the role of palliative care. One way of improving both their knowledge and engaging them in palliative care service, could be through appropriate social support groups for Chinese migrants such as Chinese community centres where community workers could act as mediators or educators.⁴⁴

Further research

Our review focused on the perspectives of Chinese migrants' views of palliative care and those of their adult

children. To develop more appropriate palliative care services for this community, a greater understanding of the perspectives of healthcare providers delivering palliative care to this group is also required. In particular, those professionals with direct experience of working with the target population, suitably qualified and experienced first generation ethnic Chinese health professionals. Our review amalgamated findings from a heterogeneous sample of Chinese migrants from Taiwan, Hong Kong and mainland China. Although all migrants will have similar roots in their belief systems, their place of birth together with their differing cultures, customs and dialects, will influence their perspectives and their expectations to palliative care. Future studies should be conducted on these distinct Chinese populations and/or at least take place of birth into consideration when analysing their data. Studies are needed in other countries of migration beyond high-income Anglophone countries.

CONCLUSION

Chinese migrants, especially first generation, coming to high-income countries may have concerns on receiving palliative care services. This may be due to a preference for their own cultural practices, and their limited knowledge of care systems in host country. Healthcare providers in the host countries need to acknowledge that their services may be insufficiently sensitive to the differing cultural needs of this ethnic group. These include communication issues in terms of recognising differences in linguistics across Chinese populations and in how a family chooses to make healthcare decisions.

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