The role of health literacy in reducing health disparities in rural CaLD communities

Rhonda Garad^{1,2}, Lauren Waycott¹

¹Jean Hailes for Women's Health, VIC; ²Deakin University

Abstract

Title: The role of health literacy in reducing health disparities in rural CaLD communities.

Background: Approximately one third of the Australian population live outside of major cities. Those who live outside of major cities experience health disparities, higher levels of preventable deaths and a five year mortality gap when compared to metropolitan dwelling persons. Health disparities are defined as differences in the health outcomes of persons served by the same health system.

Preventable deaths are those that occur prematurely that might have been avoided through better preventive health activities such as screening, good nutrition and healthy habits such as exercise. Evidence indicates that persons with low levels of health literacy have lower levels of participation in preventative activities.

Approximately 74% of migrant and refugee groups have lower levels of health literacy compared to the general Australian population (59%) with many residing in regional and rural areas as a consequence of Australian Government settlement policies. These factors increase the risk for this cohort of preventable illness and premature mortality.

The association between the health literacy abilities and health beliefs of culturally and linguistically diverse (CaLD) groups and health disparities has not yet been fully explored. This study seeks to address this gap.

Methods: Semi-structured interviews were conducted (=45) with three CaLD groups (Somali, Chinese and Indian) from metro and regional areas. Interview content included inquiry into health beliefs, disease attribution, health information seeking and health behaviours. Data was analysed using an NVivo coding process and thematic analysis.

Results: Results show an association between health beliefs, disease attribution, health information seeking and health behaviours and engagement in the areas of: prevention, screening, early intervention and treatment compliance. Alternate health beliefs such as magico-religious, ayurveda and in traditional practices contribute to health literacy barriers and lower levels of health literacy.

Conclusion: This study has shown that there is marked variance in health beliefs, disease attribution and health seeking behaviours between and within the three CaLD groups and this information may assist those supporting the health of these rural communities to develop or adapt local level responses which account for the variance.

Background

Globally migration is increasing. The number of international migrants in 2013 reached 232 million; up from 154 million in 1990 (1). Ongoing growth in migration has implications for health systems and migrant health internationally. Discourse relating to migrant health is dominated by two globally observed phenomena; the 'healthy immigrant effect' (2) and 'migrant health decline' (3). The 'healthy migrant effect' relates to the observation that the health status of newly arrived migrants is often as good as, or better than persons born in the host country (2, 4). 'Migrant health decline' refers to the observation that migrants often experience a steady worsening of physical health following migration (3, 5-7).

The healthy migrant effect and migrant health decline

The healthy migrant effect has been observed in developed countries across the world, including; United States of America, Canada (8), UK and Australia (3) (2), The phenomena is often attributed to a number of factors such as: pre-migration selection criteria employed by many host countries (9)

which disqualify applicants with existing health conditions: healthier lifestyle norms in the country of origin (2, 5); and higher levels of social capital of those choosing to migrate (6).

Following migration however, a health decline has been detected as early as three years (7, 9-11). Observed contributors to this decline include: the adoption by migrants of lifestyle patterns from the host country (3, 12, 13); longer term impacts of exposure to conflict and trauma in migrant's country of origin (7, 14); stress associated with migration (14); stigma and discrimination associated with minority status (14, 15) and a low socioeconomic status in their host country (16) (17).

There is also a growing body of evidence suggesting that health literacy barriers unique to this cohort may contribute to the migrant health decline. Barriers such as: a lack of culturally appropriate health care services (14); lack of familiarity with the healthcare system; difficulties communicating with healthcare providers (18): methods of learning inconsistent with education offered by health care providers; religious and cultural practices, and health beliefs that are inconsistent with the norms of the host country, continued use of traditional medicines and therapies, and low health literacy. These issues may also contribute to lower rates of participation among migrants in: cancer screening programs (19), mental health care (20), and pre-emptive care for preventable conditions (21-23).

The role of health literacy in migrant health decline

"Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course "(24) Low health literacy has been associated with a range of poor health outcomes including increased hospital admissions (25, 26), poorer disease outcomes, and increased mortality (26, 27). A review estimated that in the USA, limited reading and numeracy adds approximately 3-5% to annual healthcare costs (28).

Although existing studies indicate a link between lower rates of health literacy and health disparity among immigrant populations (29, 30), empirical research on this topic is incomplete. Internationally, migrant groups have been observed to have lower levels of health literacy than persons born in the host country (18, 31, 32). However, the health literacy of migrants may be misrepresented due to limitations in health literacy measurement practices. Criticisms of current health literacy measures include the use a narrow set of conceptual dimensions, and poor psychometric properties (33, 34). In addition, studies of migrant health literacy are often inadequately powered to ensure reliability across subgroups (i.e., race, age, ethnicity, and gender) (34) and show bias towards those with those with higher English proficiency (35).

In addition, there is little guidance to support health services in the development of culturally and contextually appropriate interventions which target health literacy to augment health equity (36)

Rural health disparities

There is a mortality gap of over five years between urban and rural populations in Australia according to the National Health Performance Authority (NHPA) Report (2013) (37). Life expectancy at birth ranges from 83.6 years in metropolitan areas to 81.5 in regional hubs and 78.2 in rural places. The number of avoidable deaths is also higher with 115 in metropolitan areas compared to 171 in regional hubs and 244 in rural places per 100,000 persons. This trend showing poorer health outcomes in non-urban areas is similar for hospitalisations and cancer survival rates.

The factors accounting for the health disparity between urban, regional and rural areas are complex. The NHPA report indicates there a number of structural barriers that exist for populations residing in regional and remote area such as: reduced access to health professionals, private hospitals, and socioeconomic differences. In 2012-13 there were 5.8 GP services per head funded by Medicare, compared to 5.9 in inner regional areas, 5.2 in outer regional areas, 4.1 in remote areas and 3 in very remote areas. In addition there is less access to private hospitals, even for those who are privately insured. Socioeconomic differences between urban, regional and rural populations are also considered to be a contributing factor. Only 36% of persons living in outer regional areas have adequate levels of health literacy compared to 42% in metropolitan areas (38) which may also contribute to the health disparities.

The differences in health literacy between metropolitan and non-metropolitan areas may be also explained by socioeconomic differences. A strong social gradient exits between metropolitan and non-metropolitan areas and in health literacy (30, 39). For example, educational levels have been shown to influence health literacy by impacting competencies such as reading ability, or how easily individuals can read existing health-related information such as medical forms, treatment regimes, medication labels, and patient educational materials (40) (18) (41) (30) (29). Income levels are also associated with health literacy abilities (42) with the median gross household income (2011-12) in cities across Australia 1.37 times higher than for the 'balance of state' (43).

Whilst half of all migrants in Australia live in metropolitan areas such as Sydney or Melbourne (44), many locate to rural and regional areas as a result of Australian settlement policies (45). Under the two migrant entry schemes: The Skilled Regional (Provisional) visa (subclass 489) and The Regional Sponsored Migration Scheme (RSMS), migrants are placed in regional areas in need of skilled labour.

Immigrants living outside of metropolitan areas face increased stressors which are likely to compound the rural health disparity for this population. According to a report (46) from the Federation of Ethnic Communities' Councils of Australia (FECCA) migrants in regionals areas are further disadvantage due to factors such as: lower quality human service infrastructure (e.g. settlement services and mainstream services providing assistance targeted to diverse community needs), social isolation (for both individuals and small communities), racism, labelling and stereotyping, difficulty with finding employment, or avoiding exploitation (particularly for seasonal workforce) and limited access to the cultural and religious institutions necessary for the preservation and celebration of heritage and identity.

Study aim

The aim of this study is to uncover the factors that support and inhibit those from migrant and refugee groups in Australia, to gain access to, understand, appraise and apply health information to take decisions in everyday life concerning healthcare, disease prevention and health promotion.

Specifically the study seeks to uncover;

- The similarities and distinctions, in terms of conceptualisations of health, between three distinct migrant communities in Australia
- How cultural interpretations of health within migrant and refugee groups influence health literacy

Ethics approval

Ethics approval for the study has been obtained from the Human Research Ethics Committee of Deakin University and from four of the participating sites. Written informed consent will be obtained from all participants (Approval number 2013-188).

Methods

Semi-structured interviews were conducted (n=45) with three representative CaLD groups (Somali n=15, Chinese n=15 and Indian n=15) in metropolitan and regional areas. Interview content included inquiry into health beliefs, health information seeking, disease attribution and health behaviours. Data was analysed using an NVivo coding process and subject to thematic analysis.

Recruitment

Study participants in each group were recruited within metropolitan Melbourne and regional areas of Victoria using two key strategies:

- 1) direct invitation to participate; and
- 2) snowball recruitment.

Chinese and Indian participants

Both Chinese and Indian groups were recruited through an invitation to participate process. A bilingual health worker from the Multicultural Centre for Women's Health organisation assisted with the

recruitment of both groups through the distribution of an e-mail invitation to community group coordinators in metropolitan and regional areas. The leaders provided the information to members of their groups. The names of those willing to participate were then forwarded to the PhD candidate.

Somali participants

To recruit members of the Somali community a snowball strategy as the community are more willing to respond to channels of known associations, rather than to persons they have had no prior contact with. Leaders of the community were approached to assist with recruitment.

Advisory Group

Three advisory groups were established to provide advice and guidance on areas of cultural safety, engagement, and dissemination of project outcomes. Criterion for participation in an advisory group included; belonging to one of the three cultural groups and a willingness to guide the project to ensure the cultural interests of participants are protected at all times.

Inclusion and exclusion criteria

The study sought to include a representative sample from the participating communities. Both men and women who were born overseas, who may have one or more chronic diseases, and who identify as being a member of one the target groups, were invited to participate. Individuals under the age of 18 years, and those with cognitive impairment were excluded. The ability to speak English was not a requirement.

Interviews were conducted by the PhD candidate with the aid of a translator and were held in community centres (See appendix 1: Semi-structured interview schedule).

Results

Results indicated an association between culturally determined health beliefs and the health literacy abilities of: motivation, access, engagement and compliance.

Somali cohort

The themes which emerged from the Somali interviews (n=15) included:

- distrust of health professionals and health institutions
- alternate disease attribution
- alternate health seeking behaviours
- preference for distributed decision making
- an 'Insha-Allah' determinist approach to preventative health and early intervention.

Distrust

The majority of Somali participants expressed concern for the safety of medical interventions and the ethical behaviour of the health system. They attributed the high rates of Autism seen in the community to the Measles, Mumps and Rubella vaccine. In addition, many express fears for the inclusion of pork related materials in medicines. They also indicated concern that the health system may use African people for experimentation of new drugs or procedures.

Disease attribution

Many of the Somali participants attributed disease causation to magico-religious influences. This was particularly apparent for mental health issues which they believed are caused by external forces such as the 'evil eye' or from 'Jinns' that invade a person and alter their behaviour. Religious leaders such as Shieks were primarily consulted to assist in warding off these external forces. Many also indicated that social interaction acted as a therapeutic intervention for depression and anxiety. In addition, they also expressed a strong belief that 'chemicals' in the food and the environment were the cause of many diseases.

Alternate health information sources

The majority of the Somali participants received health information via mechanisms outside of the Australian health system. The main sources were from the Australian Somali community or the Somali diaspora. A key source of information was a UK based medical program delivered by Somali doctors. Few of the participants used written or digital health information sources or participated in prevention activities or programs such as screening with a low level of confidence in early intervention approaches. Also, they indicated confusion at disintegrated health promotion messages broken into the domains of physical, emotion or psychological health. They had a preference for more holistic simplified information.

Distributed decision making

The majority of participants indicated a preference for distributed decision making in relation to health issues.

Insha-Allah

There was a strong belief in a 'determinist' view of health and limited belief that non-religious influences could overcome the 'Will of God'. This belief deflated the significance of prevention activities.

Chinese cohort

The themes which emerged from the Chinese interviews included:

- traditional Chinese practices
- · cultural health networks
- low levels of acculturation
- somatic expression of mental health
- integrated health messages
- preference for distributed decision making.

Traditional Chinese practices

Many of the Chinese participants indicated a strong preference for and belief in traditional Chinese medicine. Many utilise the health system for acute illness and consult traditional practitioners for chronic conditions. Some participants indicated that they had returned to China for treatment when faced with a serious illness. Few disclosed to their general practitioners their use of traditional medicines and therapies. Great concern was shown for the delay in access to specialist services.

Cultural health networks

The use of cultural health networks was highly favoured as a primary source of health information and support.

Low levels of acculturation

Many participants indicated they have continued with Chinese lifestyle practices, such as diet and social connection, and a low level of adaptation to Australian lifestyle practices.

Somatic expression of mental health

The majority of participants indicated low levels of acknowledgement and high levels of social stigma associated with mental health conditions. Chinese persons experiencing mental health conditions were more likely to express somatic symptomology such as headaches, insomnia etc. than acknowledge they were experiencing mental health issues.

Preference for distributed decision making

Many participants indicated a strong preference for distributed decision making which is an "...ongoing event that often evolves over several encounters...and distributed over a range of people" when making health related decisions.(47)

Indian cohort

The themes which emerged from the Indian interviews included:

- traditional medicines
- discrimination
- distrust

Traditional medicines and practices

Many Indian participants indicated a high level of satisfaction with use of traditional medicines and practices such as ayurvedic and homeopathic medicine. Few participants indicated they disclosed this use to their general practitioner. Some participants indicated they used traditional medicines over conventional medicines as they believed they were more effective.

Discrimination

Some participants indicated that they felt discriminated against when receiving health care. The discrimination was particularly noted in emergency care when participants indicated they were left waiting for longer periods and the attitude of some health professionals was more negative towards them than other groups.

Distrust

Some participants indicated strong distrust of the health system which they believed used excessive and perhaps harmful levels of testing. This was particularly apparent with pregnant women, with anecdotal evidence of women returning to India for the duration of their pregnancy.

Limitations

This study was conducted with Australian migrants within the context of the Australian health system and may not be fully generalisable to health systems in other countries. For example, cost barriers were not identified as a major access barrier which may not be the case in other countries.

In addition, this research is based on a relatively small number of subjects and the sample was derived from those willing to participate. This may indicate a level of self-selection and may not be an unbiased sample.

Discussion

Many previous studies have identified low health literacy abilities within non-English speaking groups but have not explicated the contribution of culturally determined health beliefs. The study also provides evidence that health promotion materials are accessed from sources outside of the Australian health sector indicating the need to redirect resources toward more effective practices.

It is also important to highlight that the issues identified within the study is the 'lived experience' of the participants and are likely to be highly relevant; especially given the large impact health literacy has on health outcomes. A follow up study or similar studies confirming the findings may be very useful.

Implications for the health sector

Health professionals need to address knowledge deficits in the areas of disease attribution, ethical and safety concerns and disease prevention when working with CaLD groups, which will impact the health literacy areas of motivation, access, engagement and compliance. In addition, greater inquiry is needed into the use of traditional medicines which may improve safety and health outcomes. Also, the health sector needs to enable distributed decision making and to view the high level of social cohesion as an opportunity for health education.

The sector needs to reorientate health promotion resources toward more effective approaches such as the development of visual education materials which use cultural relevant narratives and provide holistic health messages. In addition, the use of outreach education programs delivered by bi-lingual health educators will have greater utility with these groups.

Many CaLD groups face unique health literacy barriers and those who live in rural areas are further disadvantaged by issues such as reduced access to health services, lower levels of social support, fewer support agencies and discrimination.

Conclusion

Culturally determined health beliefs impact the health literacy abilities such as motivation, access engagement and compliance. A more comprehensive understanding of the health literacy barriers and enablers for migrant populations in Australia will assist agencies to more effectively meet the needs of this group. The outcomes of the research will inform practice and policy, and enable practitioners and organisations to address the health literacy needs of migrant communities.

Appendix 1: Semi-structured interview schedule

Seeding question

Thinking about the experiences of (Chinese/Indian/Somali) people in Australia in trying to look after their health (or the health of their family), what do they need to assist them to find understand and use the information and health care they need?

Guiding interview questions

If you or your family are sick where or to whom do you go to seek help?

What are some of the difficulties in getting help when you or your family need it?

Where do you get information about health?

What have your experiences of health care been like in Australia?

Do you understand what the doctor or nurse is telling you?

If you did not understand what the doctor or nurse said would you ask questions?

Do you follow the doctor's instructions? Who do you trust to provide you with health advice?

In your home country, if you or your family were sick, where and to whom did you go to for help?

What does health or wellbeing mean to you? What do you believe makes you healthy?

What do you believe makes you sick? What does health prevention mean to you?

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Presenters

Rhonda Garad has a background in health service delivery and has worked in the area of public health and health promotion for the last decade. She works at Jean Hailes for Women's Health as a health educator and project manager with expertise in research translation and dissemination. She has a particular interest in health equity with a focus on the health needs of minority groups. Rhonda holds a Masters of Public Health and is currently completing her PhD in health literacy at Deakin University.

Lauren Waycott has a background in public health and health promotion and has extensive experience in healthy literacy research and the delivery of health promotion activities. Lauren works at Jean Hailes for Women's Health as a project officer in the translation department, as well as at Deakin University in academia. She is interested in reducing health inequalities; and the provision of equitable interventions to improve health outcomes in marginalised populations.