

Building information resilience: How do resettling refugees connect with health information in regional landscapes - implications for health literacy

Abstract

The study explores how resettling refugees experience a new health environment and develop health literacy practice. The concept of information resilience, which emerges from the grounded experiences of learning to live well is introduced. The study also explores how health narratives are constructed, disseminated and circulated by this particular cohort.

Keywords: Health literacy; refugee health; information seeking; information use

Introduction

Unlike migration, which is planned and controlled by the migrant, the movement of refugees to new countries is often beyond their control. The forced movement and displacement of people across the globe is fraught with economic, social, and historical difficulties, that impact on many levels of refugees' lives including their health and well-being. A significant factor for refugees is the disestablishment of their local information landscapes and knowledge practices as they are forced to move away from their familiar environments, social alignments, information sources and ways of knowing. The transition towards and into a complex and unfamiliar new information environment requires that resettling refugees enable their reorientation by engaging with a range of new information sources and recognizing ways of knowing that will support the construction of new information landscapes.

The majority of refugees arriving in Australia are resettled within metropolitan areas, where language support, cultural groups and access to a wide range of face-to-face services is available. However, government policy (Department of Immigration and Citizenship, 2013) in the last few years has actively encouraged a move towards regional resettlement. This has created a unique set of challenges for resettling refugees, who often arrive in regional centres without proficient literacy or language skills, and without the support of previously arrived and established groups who have

developed expertise through their own resettlement experience. In the context of health, these barriers impact on refugees' ability to connect with and navigate the complex and challenging health information environment. In particular, they limit refugees' ability to understand the structural and operational aspects of the health system, limiting the potential for agency in decision-making and self-management of health.

Understanding how refugees connect and engage with health information and their experience of the health information environment is a significant issue for health information providers and service providers who support refugee resettlement. In addition, understanding how health literacy practices are developed in populations where language and literacy may provide a barrier to health information is an important endeavour. This is especially so given the importance of providing adequate, appropriate and targeted health care to this group. There is a strong relationship between low health literacy and social disadvantage, with a high prevalence among people from culturally and linguistically diverse (CALD) populations being reported in the literature (Hawking, Kantayya, Sharkey-Asner, 2010). Implications of poor health literacy are higher health costs and a greater burden on the public and private health systems (Australian Bureau of Statistics, 2009). Health care providers and governments need in-depth information about refugee health-related information practices to develop health education programs and health literacy instruction that targets the needs of this group.

The project reported here explores how refugees experience a new health information environment. In particular, it describes how refugees gain knowledge of health related information sources and explores how health information practice and health related literacies are developed. In this study, the construction of resilience as a response to uncertainty is explored through the concept of *information resilience* that emerges through the grounded experiences of learning to live well. The study considers how health narratives are constructed, circulated and disseminated by this particular cohort. Implications for researchers and policy makers who wish to understand the nature of refugee information experiences and health literacy are considered. The research findings are also important for the librarians in the public sector who may be called upon to support the health information needs of refugees.

Who are refugees? The Australian context

A refugee is defined by the United Nations as a person ‘who owing to a well founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion is outside of the country of his nationality and is unable to or owing to such fear, unwilling to avail himself of the protection of that country’ (United Nations, 1951). Refugees have not voluntarily chosen to leave their home country; they may arrive with or without family members, be devoid of any possessions or lack financial means of support. They may be survivors of torture or have witnessed it firsthand. In this study the category of refugee is used to refer to people arriving under a number of subclasses, i.e., in-country Special Humanitarian, Emergency Rescue and Woman at Risk visa subclasses (Department of Immigration and Citizenship 2011). In 2010-2011 period, 13,799 people were accepted by Australia in the humanitarian program (Department Immigration Fact Sheet, 2011).

All refugees are subject to health screening as part of their resettlement process. In Australia refugees are provided with the same rights to health care as permanent Australian citizens (Bywood, Katerrl and Lunnay, 2011).

Literature review

In the information studies field, with its specific interest in understanding information experiences, behaviours and use, there appears to be little published research related to resettling refugees or the information challenges or issues faced by this group. Reviews of the literature in information studies which focus on immigrants (Caidi, Allard and Quirke 2010; Quirke, 2011) indicate a lack of empirical studies that systematically explore how new immigrants seek and make use of information. In Australia, studies in the information studies field, which have focused on regional resettlement demonstrated that transitioning into the Australian environment is complex and fraught with difficulties as people learn to reconcile their own cultural understandings with those of their new countries (Lloyd, Lipu and Kennan, 2010; Kennan et al. 2011; Lloyd et al. 2013). In these studies, neither the health experience or health information literacy was explicitly studied.

In the areas of public health and global studies, a number of systematic reviews have been conducted internationally that describe the health/medical needs of refugees, which may inform a developing research agenda into refugee health literacy. In response to these reviews a range of health service models has been developed. However, as Owen, Grootemaat, Samsa, Fildes and Eagar (2009) note, these reviews are limited because they focus on the medically driven aspects of well being (e.g. identification of disease), rather than social determinants that influence the ‘social, emotional, community, cultural, language and practical problems that are part of the refugee experience’ (1). Of the research that does focus on the social determinants related to refugee health, several common structural and social barriers have been identified (Clarke, Gibert, Rao and Kerr, 2013) which can inform the present study.

Barriers: cognitive, social and structural barriers

Arguing that ‘refugee health remains a low government priority’, Sheik-Mohammed et al. (2006, 594) undertook a study of sub-Saharan refugees in metropolitan Australia. These authors employed a structured survey to explore the barriers to health care for this newly arrived cohort. In addition to language and financial barriers, these authors identified a lack of health information and poor knowledge and understanding of how to access health information sources (594). The authors noted that this situation was alleviated when refugees established connections with community and religious groups who could facilitate the delivery of information about health services.

In a campaign to improve refugee access to primary care, Milosevic, Cheng and Smith (2012) described the major issues that impact on access to health care. These were identified as unfamiliarity with the health system and how it operates; language barriers; and trust issues, which create anxiety (147). From a service provider perspective, issues included time constraints and unfamiliarity with refugee health issues.

The significance of trust issues has been highlighted by Bywood, Katterl and Lunnay (2011) in the context of torture where many refugees have been subject to torture that involved the medical profession. From a health information perspective, this has

implications for the ability of health service providers to deliver information, or may lead to information avoidance (Johnson and Case, 2012).

Cultural beliefs and information

There is limited research that targets the role of health information literacy in shaping the health information experience of resettling refugees. The need for accessible and comprehensible information that can contribute to health outcomes for minorities and migrants, has been highlighted by Allen, Matthew and Boland (2004). These authors highlight the need for culturally appropriate information. They suggest that providing access to information via libraries and the web is not enough, but should involve collaboration with consumer and patient educators to develop appropriate resources and programs that meet the information needs of CALD groups in culturally appropriate ways.

Cultural beliefs have been identified as creating barriers to health information. In a study of refugees' health experience post-resettlement, Morris et al. (2009) report that cultural beliefs affect expectations about health care and may contribute to delays in seeking advice. These authors point out that refugees tend to resettle into countries that have vast health resources and extensive and complicated health networks in comparison to their previous experience and situation. This leads to questions about refugees' capacity to understand how the health system is navigated, to recognize appropriate information and to utilize the resources that are available to them. Negative experiences with overseas health authorities (in country of origin and in transit) were identified as creating a barrier to engaging with health authorities in resettled sites.

Cultural norms and mores may further complicate the relational demands of information seeking and avoiding (Baldwin and Hunt 2002; Goldsmith, 2001). Studies in the US have shown that in some cultures (i.e., family centred cultures such as Chinese, Vietnamese, Cree and Ethiopian cultures) the responsibility of information control (information seeking, giving and withholding) and decision making are often assumed by family members rather than individual patients (Blackhall et al. 2001; Kaufert, Putsch, and Lavall, 1999; Muller and Desmond, 1992 as cited in Brashers, Goldsmith, and Hsieh, 2002).

The ability to reconcile cultural ways of knowing with the established ways of a new country has been recognized in a number of recent studies in the library and information studies field (Caidi, Allard, and Quirke, 2010; Kennan et al. 2012; Lloyd et al. 2013). Researchers working with migrants (Caidi, Allard, and Quirk, 2010) have noted that certain information (such as that about health) is often presented to migrant groups in a way that can be significantly different from how these individuals envisioned the world and how they relate to such matters. In the traditional Hmong culture, for example, those who are ill will consult a shaman, herbalist or traditional healer. Knowledge of Western health care traditions is limited to those with exposure to missionary health programs and health services provided in refugee camps, and as Allen Mathew and Boland (2004) have argued, refugees generally arrive with no knowledge of our health care system.

Adapting to a different health care culture

A lack of information which restricts access to the health care system has been linked to an inability to adapt to a new health culture by a number of authors writing from a public health perspective (Murray and Skull, 2005 ; Zanchetta and Poureslami, 2006). Working from an ethnocultural perspective, Zanchetta and Poureslami (2006) suggest that the inability to become health literate may be primarily centred on culture and language. In this respect language is viewed as the cultural tool for the transmission of knowledge including knowledge about health that embeds cultural beliefs. Murray and Skull (2005) have suggested that information seeking in relation to health and wellness may be inhibited by pre-existing cultural beliefs, and by culturally reinforced attitudes towards health care providers.

Information overload

Information overload can also affect refugee resettlement. This issue may impact on refugees' ability and capacity to understand health information when it is provided, i.e. to act on, comply or adhere to it when prescribed by health practitioners or to effectively seek information in order to reduce uncertainty. In a study on refugee resettlement in a regional setting (Lloyd et al. 2013), service providers reported on strategies employed to remind newly resettled refugees to attend medical appointments. Resettled refugees described compliance activities like 'going to the

doctors' because it is part of their resettlement phase. Interestingly, in this study settler participants indicated that 'time' to understand and process information was a perceived issue for them and this may reflect on their ability to comply and adhere to health information. Overload may be linked to information avoidance with people actively ignoring information because of external pressures or fears, thus promoting uncertainty (Brashers ,Goldsmith and Hsieh, 2000; Case and Johnson, 2013).

Conceptions of health literacy

The inability to successfully engage with an information environment that is shaped in culturally different ways and to navigate towards information sources in that new environment can impact on people's ability to make informed decisions about their health. As Johnson and Case (2013, 9) argue, an 'individual's level of health literacy determines the information base they start on when confronted with a health problem'. The need to understand how the health information environment is experienced by refugees in the construction of their information landscape, therefore, represents a significant area for research. This has implications for reviewing current understandings of health information literacy practices, to ensure that health information for refugees is targeted and focused towards the way in which groups encounter information with limited literacy or language skills.

Early descriptions of health literacy (Simonds 1974) have been prevalent in the health literature and appeared at the same time as the term information literacy was coined in the library and information science field by Zurkowski (1974). In the health field, health literacy was originally associated with the ability to read and write (functional literacy) which would enable patients to comprehend and follow the directions on a prescription and adhere to the advice of doctors (AMA, 1999). However, over the years definitions have altered as research began to identify the complexity of the health information environment. Nutbeam (2008) has described health literacy as composed of three tiers. The first -functional literacy - concerns the ability to read and write and is expressed through traditional text based views of health information. This is followed by cognitive and literacy skills that enable the ability to engage in competent dialogue with health care providers and to make meaning out of this interaction. The final tier relates to critical health literacy and the ability to critically analyse information for self-management. These last two tiers acknowledge the

complexity of the health environment and the broadening of understanding about the role of non-textual sources of information.

However, the majority of definitions appear to remain confined to the text-based model of health literacy, which underpins the medical knowledge domain where information and knowledge are considered to be fact-based, reproducible and accessible through a range of text bound competencies and information skills. Schultz and Nakamoto (2005) have focused on the range of knowledge required for health literacy and the skills required to access and use knowledge. Knowledges described by these authors are declarative knowledge, relating to how to approach a health condition; procedural knowledge or 'know-how' in the application of factual knowledge in specific conditions; and judgment skills, which enable patients to deal with novel situations. Rootman and Gordon-El-Bihbety (2008, 11) define health literacy in relation to the operationalization of skills i.e. 'the ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life course'.

A marked change in the direction of health literacy comes from Jordan, Buchbinder and Osborne's (2010) research which couples functional literacy with five key skills described by these authors in relation to ways of knowing: where to seek health information; when to seek health information; verbal communication skills; the capacity to retain and process information skills; and, assertiveness related to the ability to fully understand information that is derived from health professionals. For scholars in the information literacy field, these definitions will present no surprises; they do, however, serve to represent a good example of information literacy in context.

In summary the literature review has identified that in Australia and elsewhere a lacuna exists in the research into refugee health information access and use. This has implications for health literacy, particularly for understanding how health literacy emerges in groups where English is a second language. Existing models fail to take into account how health literacy emerges when language and literacy skills are not adequate to cope with new health information environments. Consequently, a critical

starting place is to explore how people with a CALD background experience a new health information environment.

Research Methodology

The study employed a qualitative methodology, described here as the landscape methodology (Lloyd 2006), and drawn from sociocultural perspectives of constructionism and practice theory. The study focused on how refugees build an understanding about the health landscape within their new country and develop ways of knowing (Lloyd 2010) to inform their health related decision-making and their health information literacy practice.

Landscape approach

The landscape approach introduced here recognises landscapes, in the qualitative sense, i.e. as not having a physical form, but as representing a *knowledge space* that has resonance with people who are involved in collective practices, endeavours or situations. Landscapes therefore represent the total relations that exist between people who engage in similar performances (Ingold 1994). Landscapes are constructed through access to social, textual and physical information modalities that are relevant to the practice, endeavour or situation (Lloyd 2006). This access is shaped by an array of socio-cultural and socio-material practices. Information landscapes can therefore be viewed as complex information ecologies, which frame particular discourses and narratives and thus entwine people within time and place (Lloyd, 2006; 2010).

This approach views landscapes as being drawn from larger and more complex information environments. A health information landscape is socially constructed and emplaced within a larger health information environment, which is in turn composed of a wide range of domain specific and structural knowledges.

The health information landscape may be centred on particular knowledge (e.g. diabetes, chronic disease management etc.) and ways of knowing how to access this knowledge. It will have spatio/temporal features locating it within time, e.g. in context of a health information need, and connect to spaces, such as the locations

related to health, or the intersubjective spaces where people agree upon health, e.g. discussions, conversations, narratives.

Connecting with a landscape requires that newcomers operationalize ways of knowing on two levels. The first focuses on the landscape's structure and on ways of knowing how the structure is shaped, how to navigate within the landscape and how access to information is operationalized - it is therefore epistemological in nature. At another level, people engage with situated knowledges of the landscape (the 'know why' knowledges). At this level they are engaging with the ontological nature of the site, in this case knowledge related to health.

To summarize, the landscape approach emphasises the ongoing interaction of people with the socio-cultural, historical, political and material-economic conditions of their setting. There is an emphasis on the construction of knowledge and shared ways of understanding (Gergen 2001; Tuominen, Talja, and Savolainen, 2005). When a landscape approach is employed in information studies, the emphasis is on understanding how the landscape is shaped and how a person is 'stirred' into the landscape by others. There is a focus on what enables and what constrains people's construction of the landscape.

Study aims and objectives

The aim of the current study was to identify how resettling refugees experience the process of connecting with their new health information environment. This aim was supported by the following objectives:

- to identify how resettling refugees develop awareness of their new information landscapes;
- to understand the information seeking activities that new settlers employ to inform their decision-making in relation to health and learning to live well; and,
- to identify social conditions and practices that enable and constrain new settlers' ability to shape their information landscape and inform their health literacy practice.

Sample

The sample for this study comprised 20 participants, mainly of African background, which in itself is diverse, with no clear language/cultural group being represented in the sample. The majority of participants originated from the Sudan, Rwanda, Congo and Uganda. A minority originated from Myanmar (Burma). Participants had been resident in the regional town in which the study was conducted from one year up to seven years. While from differing areas, these groups all shared a common experience: they arrived in Australia as people who are dispossessed and have fled their countries because of fear of persecution and were all resettling in the same region. Participants comprised seven males and 13 females with an age range of 20-47. All participants indicated that they had arrived with limited English language skills.

Data collection and analysis

A grounded theory approach was employed in collection and analysis of data. Face to face semi-structured interviews were conducted. The use of interview technique for this study allowed a slower pace for conversation and ensured that interview questions were understood or were able to be clarified to the participant's satisfaction. Face-to-face interviews were audio recorded using an iPad application and then transcribed by transcriptionists with complex accent training. The interviews were checked by the researcher against the audio recording. Prior to interviews being conducted, the study was carefully described for participants by caseworkers who distributed the information sheets to refugees who attended the regional Multicultural Centre. The study was described a second time to potential participants by the researcher prior to the consent form being signed. Participants were asked to make a self-assessment of their ability to understand English. As participants' oral and written literacy had already been assessed by the caseworkers, this second assessment was to ensure that all participants were clear about the study aims and were able to provide informed consent. Prior to the study commencing participants were offered the use of a trained interpreter. No participant in the study requested this service.

Vignettes representing the combined voices of participants and quotes used in the article are italicised. The names of participants have been changed to maintain confidentiality.

Coding

The coding for this project aimed to identify the common issues that emerged in participants' descriptions of their health information experience. Two rounds of coding were undertaken. The first round aimed at primary coding to develop themes. The second round was employed to further unpack the coding categories (Charmaz 2006). The overall aim of this process was to produce an analysis with a range of sensitising concepts which would allow the connections between the local world and the larger social structure (health information environment) to be identified (Charmaz 2006, 133). Common experiences and themes are displayed in the vignettes, which represent the major categories of the data.

Experiencing the health information environment: Learning to live well

Connecting with the health information environment is a significant experience of resettlement. Learning to live well represents the competence of people to build resilience by improving their ability to recognize and engage with a wider range of information pathways and sources and ways of knowing (Lloyd, 2006) and to reconcile previous practices related to accessing and using health information against the established pathways of the health systems in their new country.

By identifying and connecting with others already familiar with the health system, resettling people become oriented towards the health environment and towards the various landscapes within that environment (e.g. routine medical, psychological/counselling, chronic illness). Connecting with information about health facilitates *orientation*, where people become familiar with the shape of the health information environment and systems and begin to construct the paths, nodes and edges of their information landscapes. *Orientation* acts as the catalyst for *adjustment*, and *reframing* in relation to the health environment and system and to the information related activities and skills that will link refugees to relevant and appropriate information sources. Language and literacy barriers often result in a fragmentation of knowledge, and refugee groups in the study responded to this situation by the collaborative coping strategy defined as *pooling*, whereby the fragments of knowledge they possess are *pooled* together to create a more comprehensive picture of a situation. These themes are highlighted in a series of vignettes, in the following section.

Theme One: Orienting

Vignette:

Kelsy arrived from Rwanda, with limited English language and literacy skills. Kelsy asked to come to a regional town because it is quiet, calm and uncrowded. Upon arrival Kelsy is received by case workers and introduced to volunteers from a faith-based group who will assist with resettlement. In the first few weeks, medical arrangements are made on her behalf, and she is taken to appointments at the doctor's and counselling services who treat most refugees in the area. Kelsy is shown the hospital and the location of other health services including the pharmacists. Caseworkers and volunteers tell her about how the health system works and what sort of government assistance she can receive. Kelsy is gradually learning how the health system works and how to access the information about the various services. She is advised that she can change doctors if she wants ("Why would I?" she asks). She is given information about diet and advised on the importance of good nutrition and attends workshops which describe the importance of having a healthy diet and regular visits to the doctor. According to Kelsy there is no need to seek health information because it is readily supplied, although not often in the form that she can understand. Kelsy prefers that information is provided as a written script, so that she can take time to read it carefully and deal with the language. She has identified people at her church where she can take the script to for advice and to ask their opinions. Having information written down means you don't have to remember it or where to find it – it is right there—and this is important when you are learning a new language. Over time Kelsy becomes familiar with a range of health related information sources, and she knows that if she does not understand she can contact her caseworker or someone from the faith based group where she is a member and they direct her to the appropriate sources.

This vignette describes the positioning of participants towards the health environment and its systems, and towards the range of information sources and physical sites that contribute to building knowledge about the health information landscape. Orienting is a physical and visual experience, which reduces the stress of uncertainty that comes

from experiencing a significantly different information landscape or at times when people experience information overload. The role of intermediaries is acknowledged introducing participants to relevant information sources and assisting with the navigation of the information environment.

Another participant articulated a common experience among participants:

“When I came from Africa and entered this country, I know nothing, I was confused about everything, because I don’t know where to go. I don’t know what to do”
(Renee).

The construction of the health landscape in the early stage of orientation is experiential with participants describing how they were *shown* places, which allows them to connect with information at a visual level. Participants in this study reported being taken to the medical appointments and having the health environment mediated and information interpreted for them by volunteer and case workers who support this group as they resettle: *“They were the ones supporting and helping them, who explained to me how the GP works and what kinds of questions to ask”* (Renee).

In describing how the physical landscape was mapped the following participant reported that:

They took me to the women’s health. They took me to the hospital. They decided to get me registered at the doctor’s. They drove me to women and children’s health service and from there to the community dental services
(Jenny).

Outcomes of the orientation process are that resettling refugees are able to begin the process of connecting with information that in turn enables them to reduce uncertainty and start the process of adjusting to new information landscapes associated with their resettling positions. The experience of orientation is supported by oral and physical activities, which accommodate limited literacy and language skills of refugee participants.

Theme Two: Adjusting

Vignette:

Thomas is getting used to the frequency of medical visits now that he is resettling. He is modifying the way in which he seeks information when he is uncertain about his health or has an issue. Refugee camps have limited medical resources and personnel, and were only used for emergencies. In a refugee camp of two million people, the lines can be long. Thomas reports that while in the camps there was a reliance on the community in the camps for assistance and advice with medical issues. Now that he is being resettled, Thomas has access to medical and allied health personnel, resources and information on a regular basis and he is aware that he must incorporate these resources that are now visible to him as part of his adjustment to the current health information environment.

Participants in the study described the importance of modifying ways of knowing and doing in relation to information access and the strategies used to locate information. It was observed by participants that this process takes a long time, with the first year of resettlement often being marked by a lack of understanding, created by limited language and literacy skills, and a willingness to receive and accept information without question as part of the orientation process. Carmel describes a common perception among participants:

So even though people give you information at first, it can take a year or even 2 years...the first year you say yes, yes, yes, but you are not really understanding...(Carmel)

For these participants the process of adjusting required the development of new ways of knowing and new information skills. Participants reported a widening of the possible information sources, identifying a broad range of people as their primary source. This was then coupled with secondary sources, predictably, the Internet. Interestingly, in this study the Internet was employed because it allowed people time to comprehend information and to compare this understanding with others. Pamphlets and written information were considered important for the same reason that the

information was static and could be revisited as part of the comprehension and comparison process. Television, in particular medical information programs, were cited consistently as information sources, but this information used for comparison within groups when discussing health related issues or concerns.

Theme Three: Reframing:

Vignette

Alex acknowledges the significance of the village and the community in dealing with health issues. She describes the importance of the local information and advice and the emotional resonance she feels because she was connected and aligned to a larger community of people. Now resettled in regional Australia, Alex talks about the importance of collective coping, where the community help to solve the problems by pooling together the small bits of knowledge they now possess onto one basket. Alex is gradually aware that she is more isolated in Australia, and that health issues are treated privately as an individual matter by the health system and medical practitioners. This realization highlights to Alex the importance of being connected to others in a similar situation.

Becoming oriented and adjusting to new ways of knowing or doing acts as the catalyst for participants to reframe their previous health experience and cultural understanding of health and health information and to reconcile these with health practices and dissemination of health information in their resettled environments. In comparing the health environment and role of community at home with her new experiences since resettlement, Alex reflects that:

The community there is very, very important; especially let me say that the neighbours were important in concern of treatment and advice. They are really important. If you had a problem in your family they are the ones solving it. They are able to bring everything to one basket. They take care of kids while the elders go and get the traditional medicine.

Let me say here that the difference is here, the community is not concerned about your health. They are not concerned about your family. It is up to you to

know about things. If you don't have enough experience it becomes hard for you. (Alex)

Participants appeared conflicted in relation to what knowledges should be valued. A number of participants described obtaining medicines from other places, but then not divulging this information to their doctor because these medicines were traditional.

There was also conflict in relation to how and what information should be transmitted and the tension between western information dissemination practices and traditional practices. Several participants in this study recognized the difference in health practices, in particular the amount of information that is given to patients in Australia, which would not have been disseminated in the participant's home country. A participant described how being given news of a serious and life threatening illness led to anxiety:

The doctor explained...the type of sickness you have in the long run will not be good for you. In Africa the doctor does not reveal stuff to us. ..This is not good information for us. (Carmel)

Another retells the story of a community member who was told she had a limited life expectancy. The patient becomes distraught at this news and avoids information or adhering to medical advice because she now knows she has nothing to live for. The community (not her own language group, but all from Africa) come together to offer support and advice. They do not understand why a doctor would provide information that would cause distress. The study participant in retelling this story recognizes the mismatch between the evidence based practice approach and cultural ways of knowing. She states:

In Africa the doctors do not reveal that stuff to us. ...Here they are not supposed to reveal that because three quarters of African people are under stress. They are already traumatised, so if you tell them, they will decide why should I live? I better commit suicide. (Nora)

Carmel then continues to describe how she acted as an intermediary by confronting the doctor in an attempt to highlight African based processes.

I was really concerned. I said, “Why do you give all that information to her? Do you want her to die or what?” I said to tell her direct is to make her more stressed. We don’t understand counsellors, we don’t understand what they are for. And he [the doctor] said, but here we allow this, not like Africa. And then I said “Yeah but you should have prepared us, before you give the information. Now you are going to reveal the whole secret and let her go home” (Carmel)

A significant aspect that weaves through each of the themes of orienting, adjusting and reframing is the various roles of other people in supporting the transition of refugees towards new information environments.

Supporting transition and construction

The health information environment represents a significant context that refugees are required to connect and engage with as part of the resettlement and transition process. Foundational to the three themes identified above were the sources, spaces and activities that were common to participants experience in supporting their transition and in the construction of their health information landscapes. These three elements are described.

Theme Four: Constructing the landscape

Within the health information environment, refugees construct their narrower information landscapes, connecting to information sources and ways of knowing that have relevance to their particular situation. Participants identified the primary information sources that they used to construct their information landscape. These were identified as knowledge of physical locations of health services (*being shown where things were*), knowledge of social intermediaries (*knowing who to talk to*) and knowledge about how material objects (i.e. computers and mobile phones) could be used to support their information needs through the use of social media and online information resources.

Where language and literacy skills may be limited, *others* and social networks were identified by participants as the most important information sources. This follows the same trends in studies where social networks and written materials in primary language are considered to be the most significant mediums for information (Kim

and Yoon, 2012). In the present study participants identified social networks (family, friends, colleagues) as the most important source because of the ease of communicating verbally. This was underpinned by participants' lack of confidence with basic functional literacy skills (reading and writing) which created a level of uncertainty, even though most participants had been engaged with certificate level courses (e.g. certificate 3 or 4 in child care or aged care services).

In the present study other people were identified as being important for:

- instructional reasons – e.g. to provide information about how to do something (such as accessing health services). This experience occurred through everyday settings;
- mediation reasons- to assist newcomers develop their understanding of the nuances of their new landscapes;
- confirmatory reasons- to confirm that information or understanding was correct; and,
- local reasons- to interpret the content and local knowledges associated with living in a specific setting.

For people with limited literacy or language skills, health information is experienced through *others who act as formal, informal or contingent intermediaries*. Formal intermediaries were connected to institutional sources or domains of knowledge e.g. doctors, service providers. Informal intermediaries are related to socially oriented connections e.g. friends, family. Contingent intermediaries crossed both formal and informal, and represent a source of contingent information, which may only be offered at the moment of practice or be incidental to the intended information need (Bonner and Lloyd, 2011). Similar findings related to the contingency of information provision were noted by Fisher, Durrance and Hinton (2004), leading these authors to locate contingency in the construct of information grounds. According to Fisher (2006,185) information grounds can be defined 'environment[s] temporarily created when people come together for a singular purpose, but from whose behaviour emerges a social atmosphere that fosters the spontaneous and serendipitous sharing of information'.

Even though literacy and language were limited, all participants in the study reported familiarity with the Internet, search tools such as Google and applications such as Facebook, Skype and email. The digital environment was viewed by all participants as exploratory and as a secondary source of information. Similar findings were identified by Yu (2010) who astutely noted that the digital world is irrelevant if you do not have proficient language or literacy skills.

Participants in the present study indicated that the online environment was used to help provide information about health related questions or hunches prior to seeing a doctor and to supplement information that was provided. Interestingly, when asked whether they would share this information when seeing a doctor, none of the participants indicated they would, unless they doctor initiated the online search while in the surgery.

Theme Five: Finding Health information in Everyday Spaces

Participants identified a common set of everyday spaces, which represented sites to seek information and to verify or confirm the veracity of information that had been received. While these spaces acted as a direct source of information (e.g. the multicultural council), they could also serve as spaces for informal or contingent purposes where the information provided was coincidental to the original information intention. Faith-based groups demonstrate this dual purpose, whereby the majority of participants were involved in attending religious service on Sundays (primary purpose) and these occasions were purposefully used by participants as places to seek further information or to confirm information received.

Sometimes we would meet after church is over...and they give me advice. (Iris)

Coincidental conversations at the end of services could lead to other sources of information being provided which extend beyond the intentional purpose of the everyday space. Faith-based groups were recognized by all participants in the study as significant sources of information about everyday living experiences.

Other everyday spaces that form a significant element of participants' information landscapes included the library. Libraries were identified as places to get information,

to use the computers for information seeking, and to get help from ‘*the ladies on the front desk*’ (Jenny). This confirms previous findings where libraries have been viewed by refugees as trusted places to ask questions during the resettling process (Lloyd et al. 2013).

Theme Six: Pooling information

Pooling emerges from this current study as a collective coping strategy used by refugees, whose knowledge has become fragmented because barriers such as language or literacy have limited their comprehension and understanding. In this study, many participants were isolated from the support of their specific language groups but were drawn together because of the location and circumstances of their resettlement (e.g. brought together in the same town). The concept is introduced here to describe how people with limited or basic functional literacy come together to share pieces of information in order to create a picture of the issue or challenge. Pooling information allows them to inform and support their decision making in relation to health information, when their ability to understand information is limited. Pooling occurs in everyday spaces. This activity enables refugees to work together to connect with and understand the formal and established knowledge that shape the health landscapes at system level and at everyday levels where information landscapes reflect collective ways of knowing that comes through collective coping.

In the current study, pooling occurs for a number of reasons, such as when different treatment options are too expensive and alternative ways need to be found, or when it was perceived that the treatment option is not working and another solution is required. One participant described pooling of information as creating a ‘*Plan B*’. Another provided a description of pooling, whereby the group of people met to work out a solution to a medical issue, which included sharing information from other people with similar ailments, considering traditional treatments and using the internet to find secondary sources. This information may then be taken to the medical professional as a solution to the problem:

We talk about it first and then we go to the internet, one person does this. And as we are talking about it, someone is checking. We check what we know and what is available. ...and then maybe we send someone with them to explain to the doctor
(Jenny)

In discussing other options about expensive medicines Jenny suggested that:

When it is too expensive. When it is not even helping. Then we may decide ...what should we do now? What do we know? Plan B.

Discussion: The construction of information resilience: Implications for health literacy.

The findings of this study have identified that for refugees with limited literacy or language skills, the health sector represents a complex information environment that is difficult to connect with, to access, and to navigate. To cope with the complexity of the health information environment and its systems and with the uncertainty created when information is presented in difficult to access formats or ways, refugees develop coping strategies that contribute to the development of health literacy and the building of resilience. For resettling refugees, engaging with this environment requires that they reconcile their previous ways of knowing about health in order to align with new and unfamiliar information environments and ways of knowing.

For people with limited or base line functional literacy, health literacy can be achieved in other ways that enable them to engage and connect with health information. The study identified that health literacy is a socio-cultural practice and connects people with health information that enables them to:

- orient – develop ways of knowing about health information and how it is situated within the health landscape;
- adjust- draw together a variety of sources in order to make changes to ways of knowing and ways of doing; and,
- reframe- use information to make adjustment to ways of knowing and doing.

The findings presented here suggest that health literacy is composed of a constellation of activities and strategies that enable people to connect with the new health information environment, even in situations where their language and literacy skills

are limited. This creates a more holistic view of health literacy, and highlights the need for a more comprehensive understanding of the range of information sources and ways of knowing that extends health literacy's trajectory beyond functional literacy. This includes an understanding about how participants experience the health information environment, through access to a wide and often distributed network of information sources, including social and physical sources. It suggests that health literacy is a situated practice. In this respect, health literacy should be viewed the way information literacy is viewed as a social practice (Lloyd 2006) that is located in the interaction between people, and the socio-material and socio-cultural assemblages of their new information environments. Through the mediation of others, resettling refugees are able to construct their health information landscapes, by identifying ways of knowing that will enable them to access information related to their health and to the structure of the health information environment.

Emerging from this study of refugees' health information experience, is the concept of resilience, in particular the capacity to build information resiliency in groups who have been forced into new and complex environments because of circumstances beyond their control. Resilience is associated with adaptability, learning and the ability to use learning to transform, while at the same time continuing to function (Pooley and Cohen 2010). Inherent in this definition is the capacity to use information to orient, adjust and reframe in times of uncertainty or crisis. Hersberger (2013), who has focused on stress, has explored and used this concept to create awareness among librarians of how public and virtual spaces created by libraries can contribute to a sense of place for people who are homeless, abused or neglected.

Information resilience is built through collaborative coping activities. In this study, it is an outcome of pooling, which in turn supports participant's ability to orient, adjust and reframe. While information resilience is introduced here in the context of health literacy, it represents a significant concept for information literacy in general. The concept of collective coping strategies is nascent in the information studies literature, and an exploration of other literatures in psychology and sociology has found a similar situation (Kuo, 2012). Where it has been explored, collective coping refers to the process of engaging others in meaningful, purposeful and culturally congruent ways (Kuo, 2012, 4) and suggests a focus on ensuring wellbeing. Reliance on family

members or support from coethnic members (Kuo, 2012) feature in descriptions of this nascent concept, suggesting that members are drawn to other members where there is recognition of similar norms, values and experiences.

As a collective coping strategy pooling is aimed at reducing uncertainty, by collecting bits of information from a wide range of sources. This information strategy was adopted by participants when faced with uncertainty, which was created when traditional health information landscapes were disestablished or became contested due to the disruption caused by relocation. Pooling is used to cope with limited language and literacy skills that create the most fundamental barrier to information for this group. It reduces uncertainty and encourages resilience by providing the mechanism for group decision making that may be more closely aligned to culturally oriented decision making processes. In the present study, pooling of information is central to the construction of an information landscape.

The importance of recognizing the role of everyday spaces and information grounds to the health information experience indicates directions for further investigation. In the present study, information grounds operated within a number of everyday spaces including the library, the multicultural centre and faith-based groups. The nature of information grounds is considered to be incidental, and the provision of information serendipitous, to the actual intention of the location (Fisher, Durance and Hinton, 2004). However, the experience of the information ground and the potential for this experience to be repeated becomes mapped as part of the construction of the information landscape as a feature within an everyday space.

Central to the functioning of information grounds and everyday spaces may be the Strength of Weak Ties theory proposed by Granovetter (1973). This theory suggests that with close connections (strong ties) there is a potential for members to develop the same information base. Weak ties may prove more beneficial when seeking health information because they transcend the strong tie base and may offer unique perspectives or information (Granovetter 1973; Johnson and Case 2013). In the case of resettling refugees, everyday spaces and information grounds contribute to the collective coping strategy of resettling refugees, by offering perspectives and advice

that reflect the mainstream narratives to health to which refugees must connect in order to achieve effective/successful health outcomes.

In summary, the health information environment is experienced by resettling refugees in primarily non-textual ways, and is principally mediated through other people who are engaged in formal settings and within everyday spaces. To cope with fragmented knowledges that emerge when language and literacy skills are limited, refugees in this study engaged in the activity of pooling which acts as a collective coping strategy which is foundational to building information resilience.

Implications for libraries and health literacy

The capacity to make informed decisions that relate to the self-management of health or to adherence to medical advice is predicated on the ability to engage with health information. This in turn rests on the ability to understand how the complex health environment is shaped and to develop ways of knowing how information is situated and organized, how to navigate the environment to understand the veracity of the information that is available and the modalities. The task is made more difficult for refugees who enter new and complex environments, having to determine ways of knowing while at the same time coping with new languages and literacies.

The current study has demonstrated that the process of constructing a health information landscape and becoming health literate within this new context takes on a different shape for these groups. This has implications for the role of public libraries which may act as formal sites for information, or may be used by refugees as an information ground. While libraries have traditionally offered textual information related to health, this has been shown to be inadequate because of language skills. Further work is required to identify in the first instance the types of information that may be required and secondly, the formats that are the most effective for people with limited language and literacy skills (e.g. use of visual media, or living libraries).

Conclusion

Refugees' experience of their new health information environment is often determined by language and literacy barriers, and by the need to reconcile their existing understanding about health practices with those of their new country.

Through their experience of the health environment and systems, refugees become oriented towards new ways of accessing and engaging with information. They become aware of the need to adjust existing ways of knowing about the health environment, and, this in turn facilitates their ability to reframe their previously held understandings of health information with those of their new country. In the early stages of resettlement and while language and literacy skills are being established, this experience can produce fragmented knowledge, which necessitates collective coping strategies such as the pooling of information in order to cope with the uncertainty that a lack of information can produce. This strategy appears to play a role in the building of information resilience and warrants further exploration.

The experience of refugee groups in general has implications for health literacy, which has traditionally emphasized functional literacies, textual practices and the ‘individualization’ of health. The experience reported here creates a different perspective that is rarely recognized in the literature, . For people with limited or base line functional literacy, health literacy can be initiated and achieved in other ways, employing other literacies that enable them to engage and connect with health information and the health landscape. This process results in adjustments to ways of knowing and doing in relation to health. In turn refugees reframe their health experience which may lead to tensions, in particular when cultural ways of knowing about health and knowing health information conflict with western clinical practice.

References:

- Allard, Danielle, and Nadia Caidi. 2011. “A Review of Immigrant Information Practices.” *INSCAN International Settlement in Canada* 24 (Winter-Spring): 3-4.
- Allen, Margaret, Suzanne Mathews, and Mary Jo Boland. 2004. “Working with Immigrant and Refugee Populations: Issues and Hmong Case Study.” *Library Trends* 53 (2): 301-328.
- American Medical Association. 1999. Ad hoc Committee on Health Literacy for the Council on Scientific Affairs. *Health Literacy: Report of the Council on Scientific Affairs. Journal of the American Medical Association* 281: 552-557.

- Australian Bureau of Statistics (2009) Health Literacy Australian Social Trends 4102.0.
- Baldwin, John, and Stephen K. Hunt. 2002. "Information-Seeking Behaviour in Intercultural and Intergroup Communication." *Human Communication Research* 28 (2): 272-286.
- Blackhall, Leslie, Gelya Frank, Shelia Murphy, and Vicki Michel. 2001. "Bioethics in a Different Tongue: The Case of Truth-Telling." *Journal of Urban Health: Bulletin of the New York Academy of Medicine* 78: 59-71.
- Brashers, Dale, Daena Goldsmith, and Elaine Hsie. 2002. "Information Seeking and Avoiding in Health Contexts." *Human Communication Research* 28 (2): 258-271.
- Bonner, Ann, and Annemaree Lloyd. 2011. "What Information Counts at the Moment of Practice? Information Practices of Renal Nurses." *Journal of Advanced Nursing* 67 (6): 1213-1221.
- Bywood, Peta, Rachel Katterl, and Belinda Lunnay. 2011. Disparities in Primary Health Care Utilisation: Who are the Disadvantaged Groups? How are they Disadvantaged? What Interventions Work?" *PHC RIS Policy Issue Review*. Adelaide: Primary Health Care Research and Information Services.
- Caidi, Nadia, Danielle Allard, and Lisa Quirke. 2010. "Information Practices of Immigrants." *Annual Review of Information Science and Technology* 44: 493-532.
- Charmaz, Kathy. 2006. *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. London, Sage Publications.
- Clarke, Alice, Andrew Gilbert, Deepa Rao, and Lorraine Kerr. 2013. "Excuse Me, Do any of you Ladies Speak English? Perspectives of Refugee Women Living in South Australia: Barriers to Accessing Primary Health Care and Achieving the Quality Use of Medicines." *Australian Journal of Primary Health*.
<http://www.publish.csiro.au/paper/PY11118.htm>

Department of Immigration and Citizenship, National Communications Branch
Canberra. 2011. Fact Sheet 60 - Australia's Refugee and Humanitarian Program.
<http://www.immi.gov.au/media/fact-sheets/60refugee.htm>

Department of Immigration and Citizenship, Canberra. 2013. National
Communications Branch, Fact Sheet 97 - Humanitarian Settlement in Regional
Australia.

http://www.immi.gov.au/media/fact-sheets/97humanitarian_settlement.htm .

Department of Immigration and Citizenship, National Communications Branch,
Canberra. 2012. Fact Sheet 67 - The Australian Cultural Orientation (AUSCO)
Program. <http://www.immi.gov.au/media/fact-sheets/67ausco.htm>

Fisher, Karen. 2006. "Information Grounds." In *Theories of Information Behaviour*,
ed. by Karen E. Fisher, Sandra Erdelez and Lynne McKechnie, 185-189. ASIST
Monograph Series, American Society for Information Science and Technology,
Medford, New Jersey: Information Today, Inc.

Fisher, Karen, Joan Durrance, and Marian Hinton. 2004. "Information Grounds and
the Use of Need-Based Services by Immigrants in Queens, New York: A Context-
Based, Outcome Evaluation Approach." *Journal of the American Society for
Information Science and Technology* 55 (8): 754-766.

Gergen, Kenneth. 2001. *Social Construction in Context*. London: SAGE Publications.

Goldsmith, Dale. 2001. A normative approach to the study of uncertainty and
communication. *Journal of Communication*, 51(3): 514-533

Granovetter, Mark S. 1973. "The Strength of Weak Ties." *American Journal of
Sociology* 78: 1360-1380.

Hawking, Alesia O., Kanyayya, V S., and Carrie Sharkey-Asner 2010. Health
Literacy: A Potential Barrier in Caring for Underserved Populations. *Disease-a-
Month*, 56(12), 734-740.

Herserberger, Julie. 2013. "Resilience Theory, Information Behaviour and Social Support in Everyday Life." *American Society Information Science and Technology* 39 (3): 38.

Ingold, Tim. 1994. "The Temporality of the Landscape." *World Archaeology* 25 (2): 152-174.

Johnson, David J., and Donald O. Case. 2013. *Health Information Seeking*. New York: Peter Lang.

Jordan, Joanne E., Rachelle Buchbinder, and Richard Osborne. 2010. "Conceptualising Health Literacy from the Patient's Perspective." *Patient Education and Counseling* 79: 36-42.

Kennan, Mary Anne, Annemaree Lloyd, Asim Qayyum, and KimThompson. 2011. "Settling In: The Relationship Between Information and Social Inclusion." *Australian Academic and Research Libraries* 42 (3): 191-210.

Kim, Sooyung, and Jung Won Yoon. 2012. "The Use of an Online Forum for Health Information by Married Korean Women in the United States." *Information Research* 17 (2). <http://informationr.net/ir/17-2/paper514.html>.

Kaufert, J., R.W. Putsch, and M. Lavallee. 1999. "End-of-Life Decision Making among Aboriginal Canadians: Interpretation, Mediation, and Discord in the Communication of 'Bad News.'" *Journal of Palliative Care* 15 (1): 31-38.

Kuo, Ben C. 2012. "Collectivism and Coping: Current Theories, Evidence, and Measurements of Collective Coping." *International Journal of Psychology* 48 (3): 374-388.

Lloyd, Annemaree. 2006. "Information Literacy Landscapes: An Emerging Picture." *Journal of Documentation* 62 (5): 570-583.

Lloyd, Annemaree. 2010. *Information Literacy Landscapes: Information Literacy in Education, Workplace and Everyday Contexts*. Oxford, UK: Chandos.

Lloyd, Annemaree, Suzanne Lipu and Mary Anne Kennan , 2010, On Becoming Citizens: Examining Social Inclusion from an Information Perspective. *Australian Academic & Research Libraries*, 41(1): 42-53.

Lloyd, Annemaree, Mary Anne Kennan, Kim M. Thompson, and Asim Qayyum. 2013. "Connecting with New Information Landscapes: Information Literacy Practices of Refugees." *Journal of Documentation* 69 (1): 121-144.

Milosevic, Diana, I-Hao Cheng, and Mitchell Smith. 2012. "The NSW Refugee Health Service - Improving Refugee Access to Primary Care." *Australian Family Physician* 41 (3): 147-149.

Murray, Sally, and Sue Skull. 2005. "Hurdles to Health: Immigrant and Refugee Health Care in Australia." *Australian Health Review* 29 (1):1 25-29.

Morris, Meghan, D, Steve T. Popper, Timothy C. Rodwell, Stephanie, K. Brodine and Kimberly C. Bouwer 2009. Healthcare Barriers of Refugees Post-resettlement. *Journal of Community Health* 34(6): 529-538.

Nutbeam, Don. 2008 "The evolving concept of health literacy" *Social Science and Medicine* 67(12): 2072-2078.

Owen, Alan, Pam Grootemaat, Peter Samsa, David Fildes, and Kathy Eagar. 2009. *A Review of the Literature on Refugee Health*. Centre for Health Service Development, Wollongong: University of Wollongong.

Pooley, Julie Ann, and Lynne Cohen. 2010. "Resilience: A Definition in Context." *The Australian Community Psychologist* 22 (1):30-37.

Quirke, Lisa. 2011. "Exploring the Settlement Experiences and Information Practices of Afghan Newcomer Youth in Toronto" / Une Exploration des Expériences

D'établissement et des Pratiques Informationnelles de Jeunes Afghans Récentement Arrivés à Toronto. *Canadian Journal of Information and Library Science* 35 (4): 345-353.

Rootman, Irving, and Deborah Gordon-El-Bihbety. 2008. *A Vision for a Health Literate Canada*. Ottawa, ON: CPHA.

Schultz, Peter and Ken Nakamoto. 2005. "Emerging Themes in Health Literacy." *Studies in Communication Sciences* 5:1-10.

Sheikh-Mohammed, Mohamud, C. Rania MacIntyre, Nicholas Wood, Julie Leask, and David Isaacs. 2006. "Barriers to Access to Health Care for Newly Resettled Sub-Saharan Refugees in Australia." *Medical Journal of Australia*. 18 (11): 594-597.

Simonds, S. K. (1974) Health education as social policy. Health Education Monograph, 2, 1-25.

United Nations High Commissioner for Refugees. 1951. *Convention and Protocol Relating to the Status of Refugees*. United Nations Information Horizons.

Tuominen, Kimmo, Reijo Savolainen, and Sanna Talja. 2005. "Information Literacy as a Sociotechnical Practice." *Library Quarterly* 75 (3): 329-345.

Yu, Liangzhi. 2010. "How Poor Informationally are the Information Poor? Evidence from an Empirical Study of Daily and Regular Information Practices of Individuals." *Journal of Documentation* 66 (6): 906-933.

Zanchetta, Margaret, and Iraj Poureslami. 2006. "Health Literacy Within the Reality of Immigrants' Culture and Language." *Canadian Journal of Public Health* 97, Supplement: 26-30.

Zurkowski, Paul. 1974. "The Information Service Environment: Relationships and Priorities." National Commission on Libraries and Information Science, Washington DC, ERIC Clearinghouse on Information Resources, ED 100391.

