

Health Information Behavior of Speakers of Endangered Languages

Abstract

With the advent of increased attention towards language endangerment comes the need for a better understanding of how speakers of endangered languages interact with information, specifically health information resources. This paper builds on health information behavior literature and participatory research models with indigenous communities to develop strategies for future work with indigenous communities of speakers of endangered languages, proposing a participatory methodology for future work with communities of endangered language speakers related to health using ethnographic interviews and focus groups. Lack of infrastructure, multilingualism, and distrust of outsiders are found to be major barriers between this population and health information resources. Approaching health information behavior research with an interdisciplinary and participatory model incorporating ethnographic and linguistic field methods into traditional information behavior methodologies can mitigate the challenges these barriers present. Understanding the health information behavior of speakers of endangered languages will aid in future efforts to make health information resources accessible to wider audiences and to document Indigenous Knowledge (IK). Currently, fieldwork with speakers of endangered languages is confined to linguistic and anthropological investigation. Through the proposed methodology, community members can work alongside linguists and information professionals to create culturally appropriate health information resources in their native language.

Keywords: health information behavior; Indigenous Knowledge; language endangerment; ethnography; linguistics; participatory research.

1. Introduction

In recent years, information professionals have turned more attention to indigenous populations, especially in the area of health information behavior (e.g., Aubert, 2013; Hunt and Shoaps, 2018; Morales and Zhou, 2015; Povey et al., 2016; Puzska et al., 2016; Reisinger and Ripat, 2014). Still, indigenous populations are severely underserved. These populations face serious health risks, such as heightened rates of suicide, infectious diseases, and domestic violence (Romaine, 2016: 53-54). Focused consideration of these unique populations will enable information professionals more effectively serve their needs.

Mirroring this rise in health information behavior research with indigenous populations, the urgency of language endangerment has driven an increase in language documentation and revitalization efforts. In addition to linguistic and cultural diversity, language documentation and revitalization projects preserve indigenous knowledge (IK), oral histories, and traditional ecological knowledge (TEK). At the intersection of health information behavior research and language documentation lies an opportunity to discover and preserve the knowledge encoded in languages facing endangerment.

At the most conservative estimate, 34% of the world's languages are endangered^[1] (Belew and Simpson, 2018). Language endangerment is caused by combinations of political, environmental, economic, and sociolinguistic factors. Just like language, information about traditional health practices is passed on through intergenerational transmission. When intergenerational transmission is broken, both the language and the invaluable information embedded within it are lost. Because speakers of endangered languages (SEL) and indigenous populations are faced with multiple barriers to health information, traditional practices are more commonly used than western treatments. For example, in Nigeria, this is because of a perception that western medicine tends to be "in short supply, expensive, and often-times fake" (Ojua et al., 2013: 178). Ebijuwá and Mabawonku (2015) note that over 80 percent of the

developing world depends on traditional medicine. With clear and comprehensive knowledge of western medicine, individuals can make informed decisions between traditional and western treatments.

As of yet, there has been no research on the health information behavior of speakers of endangered languages (SELs). This paper proposes an interdisciplinary, participatory methodology to understand how SEL communities engage with health information from both indigenous and western sources. This paper is organized as follows: section 2 provides a background of related research and a theoretical foundation; section 3 outlines the proposed methodology; section 4 highlights practical implications of this methodology; section 5 concludes.

2. Related Work

Despite the increased attention to indigenous populations, SELs have not been considered from an information science perspective. Rather, work with SEL communities is focused on the documentation and revitalization of their language. It is important to note that not all indigenous communities speak endangered languages, and not all SELs identify with indigenous communities. Though most indigenous people live in rural areas, this is not true of all SELs (Romaine, 2009: 56). However, in the absence of literature on SEL communities, the literature on indigenous communities and rural populations is consulted here. This section reviews methodologies used in health information behavior studies on indigenous populations, efforts to document IK, trends in language documentation toward collaborative research, and relevant theory in information science.

2.1 Methods used to study indigenous populations' health information behavior

Two methods commonly employed in investigations of health information behavior are questionnaires and interviews, also seen in research involving indigenous populations (Dingwall

et al., 2015; Ebijuwa and Mabawonku, 2015; Ebijuwa, 2015). Distributed via mail or online, questionnaires are limited in their reach. In the case of indigenous populations and SEL communities, the infrastructure needed for this method of dissemination may not be in place, confining the respondents to those with access to an internet connection or mail service. Surveys are often seen as culturally inappropriate; the context and purpose of questionnaires distributed by mail or online may be misinterpreted by the intended respondents, especially in the case of those distrustful of outsiders to the community (Momodu, 2002; Savolainen, 2016). Other recent studies regarding health in indigenous communities (Morales and Zhou, 2015; Povey et al., 2016; Puzska et al., 2016; Reisinger and Ripat, 2014) employ individual interviews and focus groups conducted in person in order to accommodate a wider range of participants.

A current trend in studies of indigenous populations is to use information and communications technology (ICT) to disseminate health information resources. Researchers judge the efficacy of ICT methods using interviews and participatory methods, specifically Participatory Action Research (PAR) (Brusse et al., 2014; Davies et al., 2015; Puzska et al., 2016; Yeates et al., 2017). PAR is categorized by “respect for and involvement of the community in all aspects of the research process” resulting in long term engagement with the communities (Davies et al., 2015: 2). The lasting relationships with community members allows researchers to prioritize the needs of the community in their research design.

A clear limitation of these methodologies is that they do not include a mechanism to address the language barrier. While efforts to disseminate health information to indigenous populations have made great strides towards providing culturally appropriate content and involving community members in determining research goals, few projects offer health information resources in the native language of the community. Davies et al. (2015), however, use PAR to design a mobile app to educate users about Hepatitis B available in both English and Yorŋu Matha, the language of the community. Though many members of SEL communities

are multilingual, this is not true of every SEL. The availability of health information resources in users' native language not only breaks down the language barrier, but also, increases the range of domains where the language is used, fostering pride in the language.

Hunt and Shoaps (2018) provide an example of an ethnographic methodology used to assess the use of ICT by the K'iche' people, an indigenous population in Guatemala. The grounding in ethnography bolsters the interview process, yielding high-quality qualitative data. Researchers lived within the community for an extended period of time performing observation, interviews, and building trusting relationships with members of the community. Most notably, this methodology actively avoids the treatment of interviewees like objects of investigation in order to facilitate collaboration between researchers and community members. Such participatory models of research offer avenues for improvement upon the traditional interview and questionnaire-based approaches

2.2 IK Documentation

Preservation of IK has improved in recent years, most notably in Africa and Australia. With such high proportions of people relying on traditional health practices as their primary form of healthcare in Africa, Ebijuwa (2015) urges libraries to take a more active role in the preservation of IK, while Adefolaju (2014) calls for synthesis between traditional health practices and western medicine. Okore et al. (2009) highlight barriers to the preservation of IK: intellectual property issues, lack of funding, and hesitance of communities to share their IK with outsiders. While funding and intellectual property rights are two issues with tangible solutions, indigenous populations can be distrustful of outsiders for a variety of reasons, including one noted by Sithole (2007): fear that "they will not have claim to [their IK] and they will remain powerless" (p. 24). Distrust of outsiders is discussed further in section 2.4.

A final challenge noted by Adams (2007) is the difficulty of capturing this unique knowledge in a digital format. Greyling and Zulu (2010) developed a method to document IK

with the aim of maximal usability (32). The wiki format utilized in this project is highly conducive to participatory research, as community members can easily collaborate in the creation and dissemination of content, and it does not require the community to surrender autonomy of their IK in order to preserve it. Among the content created through this initiative are images, videos of traditional practices, and oral histories. The information organization is simplified into the broadest possible categories, and users input content in plain text rather than HTML or XML. Significantly, the wiki format accepts input in any language. This feature promotes the accessibility and usefulness for this system as a tool for language documentation projects as well as efforts to document IK.

Wasson et al. (2016) identify a form of IK documentation already active in many communities: the community elder ('elder archive'). An elder is a respected member of the community with information on a range of topics, including language, culture, and history. Considering an individual's repository of knowledge in the discussion of archives and IK documentation reflects the view of indigenous and SEL communities that information, especially as it relates to language and culture, is held within the community rather than externally. Reliance on inter-personal communication, especially with elders or community leaders, is identified as a characteristic of information-seeking behavior of those living in rural areas, often true of indigenous communities (Hunt and Shoaps, 2018; Islam and Ahmed, 2012; Momodu, 2002; Mtega, 2012).

A trend in IK documentation is that indigenous voices are minimized and, as a result, IK may be viewed as secondary to western knowledge (Makinde and Shorunke, 2013). This is not the case of all documentation efforts, however. The Aboriginal Health Collection, housed at the University of Manitoba, aims to include more works by indigenous writers in the collection that initially contained materials *about* indigenous health written by outside scholars. Their goal is not simply to document IK, but to create a comprehensive collection showcasing an

“Indigenous-informed approach to health,” (Linton and Ducas, 2017: 273). The shift towards greater agency of the indigenous communities is also seen in language documentation.

2.3 Methodology of collaborative research in linguistics

Language documentation is the subfield of linguistics devoted to preserving linguistic diversity. Primary language data is stored in archives, in addition to publications in journals and books, formal grammars, and dictionaries. Many archives include cultural information alongside language data. The current foci in language archiving are “expanding audiences for archives and breaking traditional boundaries between depositors, users, and archivists” (Henke and Berez-Kroeker, 2016: 412).

The emerging adoption of a participatory models aims to rectify this lack of communication and the language community’s loss of autonomy over language data. The defining factor of participatory archives is that “people other than the archives professionals contribute knowledge or resources” (Theimer, 2011: 9). This trend could be extended beyond archiving to all areas of research with SEL communities. Henke and Berez-Kroeker (2016: 425) emphasize the participatory model’s potential “not only to restore power to marginalized people but also to improve the quality of archives themselves by enhancing their contextual knowledge and value.”

Similar to PAR, the Community-Based Language Research (CBLR) model is gaining traction in language documentation, defined by Czaykowska-Higgins (2009: 24) as follows:

Research that is on a language, and that is conducted for, with, and by the language-speaking community within which the research takes place and which it affects. This kind of research involves a collaborative relationship, a partnership, between researchers and (members of) the community within which the research takes place.

CBLR aims to empower the speakers of the languages being documented who, historically, have been “systematically disempowered through being posited as objects of curiosity or surveillance” (Thorpe et al., 2016: 344). Speakers maintain ownership of all data collected and

agency over the research goals and design. Though the adoption of these models is not universal, participatory methods and CBLR are gaining favor in language documentation.

2.4 Theoretical Background: Small World Mentality

Elfreda Chatman models information behavior in her Information Poverty theory and Small World model. Chatman's work focuses on the lives of those often left out of information science studies: isolated and under-privileged populations including janitors, female prison inmates, and aging women (Musa, 2015). To investigate the claim that "economic poverty was linked to information poverty," Chatman studied groups with low socio-economic status (Chatman, 1996: 194). She proposed that people of low socio-economic class are isolated by a lack of interaction with and distrust of those outside their class, resulting in a 'small world' (Chatman, 1991). To test her propositions, Chatman collected qualitative, ethnographic data over extended periods of time. The data collection period of her 1991 study on janitors, for example, spanned over two years, combining participant observation and interviews conducted in the janitors' place of work (Chatman, 1991: 442).

The small world is characterized by an emphasis on familial relationships, which dictates that "future goals and aspirations must be constrained by the standards of one's family and friends" (Chatman, 1991: 439). Constraining ambition in this manner keeps small worlds small. Chatman discovered that the difference between groups may be too large to allow an outsider to understand the needs and realities of insiders. The insiders face a conflict in meeting their information needs: needing to consult information resources created by outsiders while, at the same time, remaining "exclusive and apart to protect their autonomy and political control" (Chatman, 1996: 194). Other features of the insider mindset are preference for self-reliance and distrust of outsiders (Chatman, 1991). The concept of insiders and outsiders is especially relevant to the discussion of SEL communities, as they are isolated linguistically, and often geographically by living in rural areas. Language barriers pose a hinderance in information-

seeking, reinforcing the insider status of a member of an SEL community, and the view of those speaking majority languages as outsiders.

While Chatman's theories distinguish groups based on socio-economic status, the present work focuses on how the status of an individual's language affects their health information behavior. Chatman's theoretical model is helpful to illustrate ways that isolated communities have been treated in the literature, the methodologies applied when working with them, and how isolated populations have been described in the context of information behavior. Because SEL communities are similarly isolated, methodologies similar to those employed by Chatman should be applied in research with these communities.

3. Proposed Methodology

The basis for this methodology and the following hypotheses is a combination of Chatman's findings on insiders and outsiders, small worlds, and information poverty, and the findings that geographically isolated communities tend to rely on inter-personal communication for information (Chakrabarti, 2001; Hunt and Shoaps, 2018; Islam and Ahmed, 2012; Mtega, 2012). Chatman's theories point to socio-economic reasons that people are confined within their small worlds. Just as indigenous communities and SEL communities are not synonymous, poverty is not common to all SEL communities. While true that fewer economic opportunities are available for those who do not speak a majority language, many SELs are multilingual, and speak a majority language in addition to their native language (Romaine, 2009: 55). It is difficult, if not impossible, to generalize the socio-economic status of all members of all SEL communities. In addition to socio-economic factors, SEL communities are affected by the digital divide and language barriers (e.g., lack of health information resources available in their languages).

1. SEL communities are distrustful of information which comes from outside of their communities.

2. SEL communities rely on inter-personal communication rather than formal health information resources.
3. The health information behavior of SEL communities is determined by the social norms of the community.
4. Literacy in a majority language expands the SEL communities' access to health information resources.[2]

This paper aims to develop a methodology for understanding the health information behavior of SEL communities. A successful methodology must take into account the connection between geographic and linguistic isolation, distrust of outsiders, and reliance on inter-personal communication in these communities. The remainder of this work will be methodological recommendations for future work with SEL communities relating to health information behavior. In addition to the investigation of these hypotheses, an ethnographic approach is strongly recommended.

3.1 Community Relations: Participatory Model

Participatory research models are guided by the needs of the community and require total equality of control over research designs, methods, and outcomes. These projects are action-oriented, aiming to promote social change benefitting the community (Community-Campus Partnerships for Health, 2019). Researchers develop goals alongside community members to suit the community's needs. The community is able to collaborate with researchers throughout all stages of the project, rather than participate passively. Though participatory and anthropological approaches aim to combat the community's distrust of outsiders, researchers will, of course, remain outsiders. This methodology aims to collect the highest quality data possible from an outsider's perspective, and center the research plan on community insights and needs.

To properly engage with the community, the researcher must live within the community and follow the lifestyle practiced there for a minimum of several weeks, engaging in cultural activities

including religious rituals, social events, as well as daily activities such as farming, meal preparation, and creating traditional crafts. The length of time a researcher stays in the community is highly dependent upon the norms of the community and the community's attitude towards outsiders. For example, Hunt and Shoaps (2018: 7) cite a 15 month period of fieldwork; Chatman (1991: 442) collected data for two years; Davies et al. (2015) took slightly over two years to complete their project. The researcher's participation demonstrates a genuine attempt to understand and aid the community, building a trusting partnership between the researcher and community members.

3.2 Data Collection

Anthropological methodologies aims to mitigate the distrust SEL communities may feel towards researchers initially. Researchers must thoroughly understand the relationship the SEL community has had with outsiders in the past. This is a primary motivation for the ethnographic approach; a setting wherein both parties fully understand each other's motivations will yield the most reliable data and provide a strong foundation for research partnerships moving forward. Hunt and Shoaps (2018: 464) caution that interviews lacking this foundation may result in participants attempting to "assist, appease, or befriend [researchers] through giving responses that they feel are desired." Ethnographic interviews and focus groups are most appropriate for the investigation of SEL or indigenous communities.

Though the answers to some of the simpler demographic questions could be easily gained with a questionnaire, the more complex questions regarding health information behavior, IK, and traditional health practices will only be answered through in-depth ethnographic interviews or focus groups conducted in person. Another key benefit of oral communication is the allowance for clarification questions, ensuring both parties understand each other (Hunt and Shoaps, 2018: 468).

Interviews or focus groups can be adapted to suit the participatory research model by developing the discussion topics alongside a member of the community (Davies et al., 2014). This practice ensures that questions and discussion topics are culturally appropriate and readily understood by community members. By developing the data collection protocol with community members, the methods (e.g., focus groups, group interviews, individual interviews) can be tailored to the community. For example, Povey et al. (2016) conducted focus groups led by one outside researcher and one researcher from the community.

Sampling methodologies for recruiting additional participants should be determined by the community. As appropriate, members of the community should be selected based on and literacy and multilingualism to determine the effects of these factors. Interviewees should be balanced by age and gender as much as possible given the availability of community members.

Interviews should cover the core themes: health information needs, engagement with health information resources, sources of health information, and barriers to health information, adapted with consultation from community members to reflect the current state of access to ICT.[3] It is imperative for questions to be open-ended and to avoid leading or suggesting responses.

It would be ideal to conduct interviews and focus groups in the target language with the aid of an interpreter. Endangered languages are unlikely to have professional interpreters available for hire; if possible, it is recommended to have a bilingual community member present during interviews to interpret. Dependent on the English proficiency of the community members, parts of interview questions will need to be translated into the target language, and responses would then be translated from the target language back into English.

Translation can lead to modifications in meaning, especially in the case of complex topics.[4] Hunt and Shoaps (2018) note a translation difficulty central to their interviews with the

K'iche' community: In the absence of an established term for 'information' (the K'iche' word closest to 'information' translates to English 'wisdom'), the researchers were forced to address such questions as "(How) is [information] culturally distinct from 'belief' or 'opinion'?" (Hunt and Shoaps, 2018: 464). Despite efforts to ensure that interviewees understand the sense of 'information' intended in their interview questions, it is possible that the concept will gain either a broader or narrower sense through translation, even with the aid of a bilingual interpreter. Interviewers must take into account the use of neologisms, both in the target language and throughout the process of translation. See Tummons, Henderson, and Rohloff (2012) and Blignault et al. (2008) for detailed accounts of the development and successful adoption of medical neologisms.

3.3 Data Analysis

Data gained through ethnographic interviews and focus groups should be analyzed using content analysis. Transcripts should be coded by core themes: information needs, engagement with information resources, sources of information, and barriers to information. Content analysis can then be performed following the "iterative pattern coding" methodology, by which trends are identified through repeated reading of the transcripts (Miles and Huberman, 1994). Through this process, additional themes will be identified, and the coding scheme will be refined to include recurring topics.

With community consent, audio and video recording is highly recommended.

Researchers and interviewees should wear shotgun microphones to ensure high quality audio with minimal interference. Video recording is especially recommended in cases where a bilingual community member translates the English interview questions into the target language for the interviewee to capture cues from facial expressions and gestures. The audio from the interviews may be processed with ELAN[5] in order to align the written transcript with the audio file. Alignment with the transcript facilitates the retrieval of audio and video throughout the

analysis. Additionally, this allows researchers to enrich the written transcript with linguistic information about intonation or hesitation typically lost in transcription. Following data analysis, researchers and community members would develop a plan of action to address the needs identified by the community.

4. Practical Implications

This model can be implemented as part of a language documentation or revitalization project to create a community-based repository for traditional health practices and IK in various forms, similar to the content created via the wiki format in Greyling & Zulu (2010). Encouraging SEL communities to create this content will increase pride in the language and culture and facilitate a thriving collection of materials accessible for future generations. It is imperative that health information be documented in the language of the community. With community consent, texts can be translated into majority languages with the help of linguists to facilitate the dissemination of IK to other user groups. Alternatively, linguists can work with SEL community members to create information resources in the language of the community.

5. Conclusions

The participatory aspect of this methodology necessarily implies that researchers will adapt to suit the needs and wishes of the community. However, the proposed methodology is not without limitations. Participatory research is a lengthy process (though Davies et al. (2015) point to this time commitment contributing to the success of their project). Translation between majority languages and those facing endangerment is an equally lengthy process, though a necessary one, in order to create resources truly accessible to all. Additionally, cultural nuances of every community have not been considered; this is not universal methodology, but rather will require adaptation with each implementation. This interdisciplinary approach combining language documentation and revitalization, participatory research methods, and theoretical grounding in information science will enable researchers both to work alongside SEL communities towards

improving access to health information resources and documenting endangered languages and IK, according to the wishes of the community.

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Appendix A: Interview/ Focus Group Guide

Information Needs:

- What are some problems you face in your daily life?
- When you have a problem, what approaches do you take when solving it?
- Can you think of a time you solved a problem recently? What was your thought process? Did you get any help?
- What websites do you go to if/when you access the internet?
- If there were a library in your community, what would you like to see in it?

Engagement with Information Resources:

- Do you keep books in your home?
- Are any of these books about health?
- Do you read newspapers?
- What other purposes do you use the internet for?

Sources of Information:

- Is there a place in your community with a collection of books?
- What language are the books in?
- What are the books about?
- Do your children use the internet?
- Do your parents use the internet?
- Are computers used in school?
- Where else are computers located?
- Are the computers free for anyone to use?
- Are there people in the community who are consulted when people have a question?
- Are there people outside the community who are consulted when people have a question?
- How do these people know how to solve problems?

Barriers to Information:

- How reliable is the electricity in your home?
- Are you able to access the internet?
- Are you able to access a computer or smartphone?
- Are there websites in your language?
- Are these websites in your language about health issues?

¹ As used throughout this work, the term 'endangered' encompasses those languages rated as vulnerable, threatened, endangered, severely endangered, and critically endangered on the Language Endangerment Index (LEI). The LEI rates languages based on intergenerational transmission, absolute number of speakers, speaker number trends, and domains of use. See Lee and Van Way (2016) for more information on the LEI. See Belew and Simpson (2018) for a discussion of the vitality of the world's languages.

² The present work adheres to UNESCO's definition of literacy: "ability to read and write with understanding a simple statement related to one's daily life" (UNESCO, 2009).

³ See Appendix A for an interview or focus group guide, to be adapted as necessary.

⁴ See Kwan et al. (2015) for a discussion of necessary cultural considerations when translating survey questions.

⁵ ELAN is a software commonly used in language documentation to align audio with written transcription. It is freely available under a GNU Public license from the Max Planck Institute. See <https://tla.mpi.nl/tools/tla-tools/elan/download/> for more information.