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Title:

The Adolescent Health Care Broker – Adolescents Interpreting for Family Members and Themselves in Health Care

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Abstract

Parents with limited English proficiency might rely on their adolescent children to interpret health information. We call this *adolescent healthcare brokering*. Using a mixed-methods, transformative research approach rooted in grounded theory, we sought to answer these questions: (a) “What is happening? What are people doing?” and (b) “What do these stories indicate? What might they suggest about social justice?” High school students from a community in which 53.4% speak another language at home were invited to participate in a survey and focus groups. Of 238 survey participants, 57.5% (n=137) indicated they assisted with healthcare tasks. When doing so, 81.7% (n=112) translated. Common tasks were reading prescriptions and talking to doctors. While some participants cited negative emotions associated with brokering, the net emotion was positive. Focus groups (n=11) revealed that tasks varied broadly in complexity and type, emotional experiences were dichotomous, and access to interpreting services and other supports was inconsistent.

This research adopts an advocacy lens and uses a mixed-methods, transformative research approach rooted in grounded theory to describe and call attention to a social justice phenomenon we call *adolescent healthcare brokering*. We define adolescent healthcare brokering as young people acting as linguistic interpreters in healthcare situations for themselves and for family members with limited English proficiency (LEP). In such situations, language acts as a barrier to health literacy and access to healthcare (Kutner, 2006). Despite this known barrier, there is a gap in the research regarding how to successfully address this situation (McKee & Paasche-Orlow, 2012).

Health Literacy

The World Health Organization defines health literacy as “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health” (“Health education,” 2012, p. 10). Health literacy predicts one’s health more than age, income, employment status, education level, or race (Weiss, 2007). In part, this is because individuals who are health literate are better able to comply with prescribed treatment and self-care regimens (Weiss, 1999). In contrast, individuals with poor health literacy have a higher risk of death, more emergency room visits and hospitalizations, and poorer mental health (Baker, Parker, Williams, & Clark, 1998; *Health literacy interventions and outcomes*, 2014; Schillinger et al., 2002; Wolf, Gazmararian, & Baker, 2005).

Health Literacy and LEP

Health literacy depends on individuals understanding both written and oral communications. When there are language barriers, meeting this requirement is difficult; thus, limited health literacy is disproportionately greater among those for whom English is not a

primary language (Kutner, 2006). Given that more than 24.5 million Americans experience LEP (*Language use in the United States: 2007, American Community Survey reports*, 2010) this issue is of national concern. To mediate this language gap, and per Title VI of the Civil Rights Act ("Civil Rights Act of 1964," 1964) and Executive Order 13166 ("Exec. Order No. 13166, 65 C.F.R. 50121," 2000), federally funded organizations must provide interpreters (Chen, Youdelman, & Brooks, 2007). Despite this legislation, the implementation has been a "patchwork quilt," varying from state to state, language to language, condition to condition, and institution to institution (Chen et al., 2007).

Adolescent Healthcare Brokering

Family members with LEP might rely on their adolescent children to interpret health information being shared or needing to be communicated. While adult children may take on a similar role, the experiences stand to be different when the child is an adolescent. In the United States (U.S.), the notion of children translating for non-English speaking parents is not new. Tse coined the term *language brokering* to describe children acting as linguistic intermediaries (1995). Katz uses the term *child brokering* to describe children of immigrants who interpret both culturally and linguistically for their parents (2014). We use the term *adolescent healthcare brokering* to make it clear the focus is on navigating the healthcare system. Though past research does document this phenomenon, (Faulstich Orellana, Dorner, & Pulido, 2003; Green, Free, Bhavnani, & Newman, 2005) gaps in understanding remain (Katz, 2014).

Mixed-Methods, Transformative Research

Mixed-methods research is the collection, analysis, and integration of quantitative and qualitative data, offsetting the limitations of one with the strengths of the other to provide a more complete picture (Cresswell & Plano Clark, 2011). It is well-suited for research about/with

marginalized and underrepresented communities (Sweetman, Badiee, & Creswell, 2010) in that narratives complement, extend, and humanize otherwise impersonal quantitative data. More recently, mixed-methods research combined with an advocacy lens has increasingly become associated with what is known as *transformative research*. Per Mertens (2003, 2009), transformative research engages culturally diverse groups to construct knowledge in ways that aid them and improve society.

Ground Theory and Social justice

Grounded theory includes researchers building theories as they progress through stages of the data analysis (Glaser & Strauss, 1967). As a method, it consists of flexible guidelines for researchers to focus data collection and inductively build theories. As an analytic strategy, researchers begin analysis as soon as data are collected and throughout the life of the study. Charmaz (2006) sees compatibility between grounded theory and social justice because of the need to be close to one's data, to be critically self-reflective and to provide for reciprocal benefits. To do this, Charmaz proposes that researchers ask the following questions:

1. "What is happening? What are people doing?" (p. 514)
2. "What do these stories indicate? What might they suggest about social justice?" (p. 517)

These questions guided both the data analysis and interpretation of results.

Purpose

The purpose of our research was to use mixed-methods, transformative research approach rooted in grounded theory to document the prevalence and kinds of adolescent healthcare brokering within a target, underserved population. Also, we sought to understand the emotional experience of brokering and to uncover existing supports and desired training.

Methods

Data were collected over three, primarily sequential, phases. Table 1 represents the research design. Details on the sample population, data collection, and analysis follow.

[TABLE 1]

Sample

With institutional review board approval, the study team used purposive sampling to recruit students from high school health education classes over four semesters. Purposive sampling is a non-probability type of sampling whose main goal is to focus on a particular set of characteristics. ("Purposive Sampling," 2012) This method was ideal to study adolescent healthcare brokering in our target community. The participants reside within a town in which 54.2% speak a language other than English at home (QuickFacts, 2015) and of the school's 4,579 students, 74.9% are Latino/ Hispanic, 63% are low-income, and 12.1% are English language learners. ("Illinois Report Card 2014-2015," 2015)

To participate, students needed to obtain parental consent and to provide assent. All 102 students from four class sections were invited to participate in phase one, the pilot survey. All 244 students from 10 class sections, over three semesters, were invited to participate in phase two, the large-scale survey. All 75 students from the second of those three semesters were invited to participate in phase three, the focus groups. To recruit participants, the health education teacher read a script explaining the study, the right to assent, and the need to obtain parental consent. Participants did not receive rewards for phase one and two, but did receive five dollars for phase three, the focus groups.

Data Collection

Pilot survey. The pilot survey asked two questions: (a) “Have you ever helped a family member with a healthcare task in which you translated information from English to their language?” and (b) “In what way did you help with this task?” Results indicated (61%; n = 102) had acted as healthcare brokers, thus validating further investigation.

Large-scale survey. A four-part, online survey was administered during health classes. Part one included demographic questions. Part two questions asked if they have helped family with healthcare tasks and translated while doing so. Next, from a list of common healthcare tasks, participants indicated which they had performed. In part three, participants identified emotions felt when brokering from a list of emotions from the Positive and Negative Affect Scale, (Watson, Clark, & Tellegen, 1988). In part four, participants identified desired training from a checklist of healthcare tasks.

Focus groups. Focus groups, compared to individual interviews, enable participants’ ideas to build from one participant to another. In our study, focus groups were used to extract personal narratives to better understand the cognitive and emotional aspects of brokering. The lead author facilitated three focus groups using these questions:

1. *Can you tell us about a time you helped a family member with a healthcare task because you had to interpret or read for them?*
2. *How do you feel when you help a family member with healthcare tasks?*
3. *When helping family members with healthcare tasks, who do you ask, or where do you go or look for help?*

To protect participants’ identity and to lessen the potential for bias during the analysis, the facilitator only referred to participants by an assigned number.

Data Analysis

Mixed-methods research includes analyses applied to the quantitative and qualitative data, as well as the mixing of the data concurrently and sequentially (Cresswell & Plano Clark, 2011). In our study, we used results from the pilot survey to assist with the design of the larger scale survey. Similarly, we used preliminary results from the larger scale survey to guide the design of the focus groups. Once quantitative data collection (via the larger scale survey) was over and data were analyzed, we compared the results to the qualitative data extracted from the focus groups to determine whether there were additional inferences to be drawn.

Quantitative. IBM SPSS version 22 was used to analyze the survey data.

Qualitative. Focus groups were recorded and transcribed by the lead author who performed three reviews. First, she looked for emerging themes and compared them to findings from the quantitative analysis. Next, using grounded theory, she re-reviewed the transcripts using Charmaz's (2006) grounded theory questions:

1. What is happening? What are people doing?
2. What do these stories indicate? What might they suggest about social justice?

Subsequently, she shared the transcripts with the other authors who reviewed them independently from a grounded theory perspective. After this open-coding, we analyzed and sorted ideas to identify overarching themes, which were then combined and adjusted to determine final themes. The lead author then re-reviewed the transcripts using the agreed upon themes. Finally, the other authors reviewed her analysis and confirmed that the transcripts were appropriately coded. This triangulation of analysis contributed to the validity of this study (Merriam & Tisdell, 2016; Patton, 2015).

Results

The research in our study shares qualities with *explanatory research design*, in which

qualitative results are used to explain the quantitative results (Cresswell & Plano Clark, 2011). Consequently, we present the quantitative results first, followed by the qualitative results.

Quantitative

Demographics. Of the 244 students invited to participate in the large-scale survey, 238 received parental consent and provided assent. Of these, 48.3% (n=115) were male, 48.7% (n=116) were female, 0.4% (n=1) identified as transgender, and 2.6% (n=6) preferred not to answer. Though a sophomore-level course, ages varied as some students were repeating the course or had transferred from another district. Regarding age, 52.1% were 14, 23.1% were 15, 17.6% were 16, 5.5% were 17, and 1.3% were 18 years old.

Regarding race/ethnicity, participants first indicated whether they were Hispanic/Latino. Of those responding to this question (n=235), 82.1% (n=193) indicated they were Hispanic/Latino. Next, participants identified with other racial/ethnic groups. Of the 193 who indicated Hispanic/Latino, 21.2% (n=41) identified one or more other groups. Of those 42 participants indicating *not* Hispanic/Latino and only a single group, 30.9% (n=13; 5.5%) were Black or African-American, 30.9% (n=13; 5.5%) were White, 16.6% (n=7; 3.0% of all 235 responding) were Asian, 11.9% (n=5; 2.1%) were American Indian or Alaskan Native, and 9.5% (n=4; 3.8%) were Other. Eleven (27.5%) of those same 42 participants indicating *not* Hispanic/Latino indicated more than one group.

Prevalence and kinds of adolescent healthcare brokering. Of the 238 participants, 57.5% (n=137) indicated they assist family with healthcare tasks. When performing these tasks, 81.7% (n=112) translated information from English into their family's primary language. Of the 238 participants, 76.9% (n=183) spoke Spanish in addition to English; 15.5% (n=37) spoke English only. Other languages spoken at home (less than 3% each) included Arabic, Creole,

Filipino, French, Italian, Punjabi, Jamaican, sign language, and Tagalog.

Table 2 reveals which tasks were brokered most frequently. The top tasks were reading prescription labels, talking to the doctor or nurse, and looking up health information on the Internet. Less common were talking to the insurance company or finding a doctor.

[TABLE 2]

The emotional experience of brokering. The emotional experiences varied. Table 3 reveals which emotions were most frequently indicated. The most frequent negative emotion was *nervous*, and the least frequent negative emotions were *angry* and *ashamed*. The most frequent positive emotions were *calm* and *confident*. The least frequent positive emotions were *excited* and *strong*.

[TABLE 3]

Desired training. The large-scale survey revealed some desired training topics were more popular than others. Table 4 reveals these topics in order from most to least. Most popular was learning *how to talk to a doctor* and *how to fill out medical insurance forms*. Least popular was *finding health services close to home*.

[TABLE 4]

Qualitative

Demographics. Eleven students from three different class sections volunteered and received parental consent. Focus Groups 1, 2, and 3 were four, three, and four participants in size, respectively. Of the 11 participants, 36.4% (n=4) were male, 54.5% (n=6) were female, and 9.1% (n=1) preferred not to answer. Their ages were 14-years-old (18.2%; n=2), 15-years-old (18.9%; n=5), and 16-years-old (36.4%; 4). All participants identified as Hispanic/Latino.

Guided by Charmaz's (2006) grounded theory questions, the following four themes (a-d)

were identified:

1. “What is happening? What are people doing?”
 - a) The kinds of tasks brokered and their complexity varied broadly
2. “What do these stories indicate? What might they suggest about social justice?”
 - b) The emotional experience was dichotomous
 - c) There was inconsistent access to interpreting services and translated materials
 - d) There was a lack of formal support for adolescents who broker.

Each theme is discussed next in relation to the quantitative findings.

Theme 1: The kinds of tasks brokered and their complexity varied broadly. Like the quantitative results, this theme responds well to the questions “What is happening?” and “What are people doing?” Also like the quantitative results, the most commonly mentioned tasks included reading prescriptions, talking with doctors, and researching health information on the Internet. They perform these tasks for family and themselves.

Regarding doctors, a Group 2 participant who interpreted for her parents, said she explains to the doctor with what her parents need help, what is the problem, and how are they feeling. A Group 3 participant said, “My grandma needed to get some injections. She didn’t know what they would do to her, so I was telling her what the doctor told me.” Another Group 3 participant said, “...my uncle, he had rocks in his stomach, so I had to translate to him what they were going to do.”

Regarding prescriptions, a Group 1 participant indicated, “I’ve read the directions on insulin shots and explained how it works.” Another Group 1 participant indicated, “Pills... I tell them how often they needed to take it.” And a Group 2 participant said, “I read the symptoms and everything for them so they are aware of what they are taking.”

Though mentioned less frequently, participants also commented on internet research. A Group 1 participant said, “We looked up things for her pills that she is taking.” Another Group 1 participant said, “We researched what the side of the stomach is. [An uncle] was diagnosed with cancer. Our grandma told us to look it up to see so we could understand better.”

Sometimes brokering is complex because it is long-term or the broker is also the patient. A Group 3 participant shared that his grandmother had been in the hospital for kidney failure. Further, “All the doctors spoke English, so we had to stay there for over a month [to interpret].” Later he said, “Over that month I had to wake up every five minutes during the night so the nurse could talk to her.” Regarding when the broker is also the patient a Group 2 participant said,

Like when they are asking you questions about your past and if you had felt that way before or been sick like that before and then you gotta ask your parents, ‘Did I have that before?’ And then your parents don’t remember sometimes.

Similarly from Group 2, a participant said, “I had a high fever and had to go to the hospital...and they’re asking my parents questions like... if I am able to take medications. My parents didn’t know what to say, so I had to interpret for them.” Another participant from Group 2 shared, “I went to the hospital because I have asthma problems, and I have a tube down my throat, and its like, ‘Okay, I’m trying to translate,’ but it’s hard to translate when you are sick.”

On the act of translating in general, some participants commented on the difficulty of finding the correct words. A Group 2 participant said, “It’s hard to think of words in Spanish sometimes.” Another Group 2 participant said, “Some words are hard. We find a way to put it down or cut the words so we can be able to tell our parents what it means.”

Theme 2: The emotional experience was dichotomous. This theme responds to the question, “What do these stories indicate?” In the focus groups, negative emotions were related to worrying about interpreting incorrectly or their family member’s health. Regarding the former,

a Group 3 participant said she felt "...anxiety because you might say something wrong. Like explaining it wrong." Another participant said, "I kinda worry about it after[wards]. Cuz like if they leave and they're kinda like 'I don't understand what's happening,' ...I worry." In Group 1, when asked about what they worry, one participant said "their health." The focus groups also revealed an emotion not asked in the survey, *annoyed*. A Group 2 participant indicated she got annoyed with

...the fact that I'm trying to do something [for] my family and then my other friends are like "oh this and this is going on" and "I don't know what to do", and it's like two situations all of the time. And it's hard for me to concentrate on one and keep myself focused on the other one

This comment reveals brokers might feel they have to juggle the responsibility of helping both family and friends.

Regarding positive stress, focus group participants pointed towards feeling accomplished and relieved. One Group 2 participant said, "I do, cuz every time I go I learn something new like a better word to use." A Group 1 participant shared, "There is some sort of relief that you are helping them, you know? They're getting that surgery done because you helped them talk it out." These comments parlay with survey results indicating some participants felt *proud* and *happy*.

Theme 3: There was inconsistent access to interpreting services and translated materials. The third theme, too, responds to the question, "What do these stories indicate?" In some settings/situations, an interpreter or translated materials is/are sometimes available, and other times not. A Group 2 participant, commenting on making a doctor's appointment said, "Yeah, there are times when they don't have an interpreter to say it in Spanish or someone that understands. Like [when] I had to make the appointments." And when at the doctor's office, a Group 3 participant said, "Two days ago my sister had to go to the doctor, and I was there interpreting for my mom. There was no one that could interpret what my mom was saying."

When at the pharmacy, a Group 2 participant said, “When we went to the store. . . .and they need their medical prescription, I have to ask.” Another participant from Group 2 had a different perspective, though, saying, “Most of the time, people speak Spanish now at pharmacists everywhere so there isn’t like really isn’t anything like that my mom needs me to help her.” When searching for health information on the Internet, a Group 1 participant said, “Most of [the websites] weren’t in Spanish. Mostly in English.” Regarding a less common brokering task, communicating with insurance companies, a Group 3 participant said she spoke with them “when there was nobody to translate for my mom.”

Theme 4: There was a lack of formal support for adolescents who broker. The last theme also responds to the question, “What do these stories indicate?” When the focus group participants were asked on whom they rely for support when brokering, the response was typically family. A Group 1 participant said, “It depends on who I go with or who I’m helping. If I go with my uncles, I’ve got my cousins.” A Group 2 participant indicated she was an only child, so she doesn’t have any siblings to help her. Another Group 2 participant, indicating her sisters helped her, said, “We know different types of Spanish. I know bigger words, but they know basic words I don’t know.” A Group 3 participant said, “I go with my sister and little brother. I’m the oldest. [They] know some words, too.” Another Group 3 participant indicated, “My older sister did, but now she has a job and she really can’t make it to the appointments.” These responses show translation is often a team approach. One Group 3 participant’s response showed how health professionals try to support the adolescent healthcare broker. He said, “I used to go to with [my aunt] since she didn’t understand the machines. They kinda simplified it for me.” And sometimes that health professional is a family member. One Group 3 participant said, “My aunt, she’s a doctor. Sometimes I ask her. Like I text her.” Another Group 3 participant

said, “My cousin. She’s a nurse. She helps out.”

Discussion

The survey and focus group revealed that the kinds of tasks brokered and their complexity varied. Participants indicated they were talking to doctors and pharmacists, researching conditions on the Internet, and communicating on behalf of their family members, themselves. While some acts were brief, others lasted as long as a month. These findings are in line with Green, Free, Bhavani, and Newman (2005) who found bilingual young people interpret in a wide variety of situations and regard those situations as unremarkable tasks of everyday life. Disquieting were situations in which participants were both the patient and the interpreter, or were worried about the health of a family member at an age when such personal information might otherwise been kept from them. Per Katz (2014), such situations complicate the roles that children traditionally play at home and in the health setting.

The survey and focus group findings also revealed dichotomous emotional experiences. Kam and Lazarevic (2014), too, found this dichotomy; however, they found adolescents who had high brokering efficacy and/or perceived that their peers were also brokering felt positive emotions. Conversely, adolescents who perceived brokering as a burden felt negative emotions. Kam and Lazeric further stated that the danger of the negative emotions is they are associated with family-based acculturation stress, as well as drugs and alcohol use. In our study, some participants worried about the health of their family member, yet were prideful about helping. Others found brokering to be a burden. Regardless of the emotion felt, it should be noted adolescents who broker carry greater responsibility in their day-to-day lives than those who do not.

When it comes to interpreting services and translated materials, the findings imply they

were inconsistently available. The survey results, by way of the variety and number of tasks brokered, supports this belief. Chen et al. (2007) indicated one of the reasons some healthcare providers do not provide interpreting services is they are unaware of their legal obligation. However, one Group 1 participant's comment revealed sometimes assistance is available, but refused. He said, "My grandma is old fashioned. She probably wouldn't take that." This statement indicates some patients with LEP prefer to rely on family to interpret. Regarding translated materials, some focus group participants wanted a list of medical terms, in both English and their family's language, to be made available upon a doctor's visit. Having such a list could easily and economically fill a language gap. A digital tablet linked to terms, definitions, images, and videos could facilitate this process.

The findings also reveal there is a lack of support for adolescents who broker, despite the existing documentation of this phenomenon (Faulstich Orellana et al., 2003; Green et al., 2005). The consequences of reversed family roles when a child takes on the role of the parent (Hua & Costigan, 2012) and the potential medical complications that could arise from misinterpreted or omitted health information (Faulstich Orellana, 2010) makes adolescent healthcare brokering worthy of attention. The wide range of topics in which participants wanted training, points to a vast and pervasive problem. While some participants mentioned they had the support of family, this should not be a replacement for language access to healthcare. This is particularly important for those adolescents who do not have others on whom to rely.

Limitations

Despite the value of this study's findings, there were some limitations. First, given that majority of those adolescents who participated in the study come from Spanish-speaking families and the majority of individuals in the community are Hispanic/Latino, there could be greater

access to interpreters or translated materials compared to communities in which one's racial/ethnic background is in the minority. This means that the findings regarding brokering prevalence from our study might actually be deflated compared to other communities where the language spoken by families is not in the majority. A second limitation was the size of the focus groups. Although the opportunity to participate was offered to 75 students, only 11 received parental consent and provided assent. Despite their smaller size, we contend the narratives *do* complement and extend the quantitative findings. A third limitation is the information not collected due to participant fear of disclosing a non-English speaking status or personal health information. While this limitation is difficult to resolve, future research must provide assurance regarding confidentiality.

Implications

Our results hold implications for intervention and prevention practices. First the results confirm that adolescent healthcare brokering is a way of life for some adolescents whose family members have LEP. Consequently, our study serves as a reminder to school administrators, health and medical professionals, and lawmakers that despite assurances from Title VI of the Civil Rights Act (1964) and Executive Order 13166 (2000), its implementation reflects the “patchwork quilt” described by Chen et al. (2007) with varying availability of interpreting services and translated materials. While brokering patterns in other communities might vary based on geographic location, languages spoken, socio-economic status, and other characteristics, continued efforts towards improving the provision of interpreters and translated materials, both locally and nationally, are needed.

Second, the results confirm a need to include direct instruction on performing basic healthcare tasks into the school health or other curriculum. Those adolescents who are acting as

healthcare brokers could share and practice those skills with family members, creating an understanding of and value for improved health literacy. Ideally, adolescents would not have to practice these skills until adulthood; however, the findings indicate they might benefit from learning those skills sooner. While there may be classmates who do not act as brokers, *all* young people can benefit from health literacy instruction as they move towards adulthood.

Third, the results afford an opportunity to propagate a more linguistically and culturally diverse field of healthcare professionals. Given that many adolescent healthcare brokers are already practicing skills advanced for their age group, a health careers focused curriculum could show them how they can transform those skills into a career. These roles could include, but not be limited to, medical interpreters, community health workers, doctors, nurses, physician assistants, and public health professionals. The benefit is that research shows that racial and ethnic minority practitioners are more likely to work in medically underserved areas and serve uninsured or underserved racial and ethnic minorities (Tolerance, n.d.).

Finally, the results validate the need for continued research into adolescent healthcare brokering. McKee and Paasche-Orlow (2012) argued for a hybridization of LEP and health literacy research to develop innovative approaches to meet diverse health communication needs. Such research should investigate both local and national needs. Local attention is needed for day-to-day care. National is needed to assure that funding is available to support such efforts, via both high-tech and low-tech solutions.

Conclusion

Per Sweetman et al. (2010), “Knowledge reflects the power and social relationships within society, and the purpose of knowledge construction is to aid people to improve society,” (p. 442). Adopting a transformative research approach rooted in grounded theory, we placed

central importance on the experiences of a marginalized group when it comes to matters of health literacy. Being able to understand health information is *integral* to one's health functioning (Singleton & Krause, 2010). In families in which the adults have LEP, they may rely on the children to act as linguistic, and sometimes cultural, interpreters. Given the connection between health literacy and health outcomes, adolescent healthcare brokering is worthy of continued research and preventive efforts as a matter of social justice.

Compliance with Ethical Standards

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Conflict of Interest: The authors declare that they have no conflict of interest.

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