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Adolescent Healthcare Brokering: Prevalence, Experience, Impact, and Opportunities

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**ADOLESCENT HEALTHCARE BROKERING: PREVALENCE, EXPERIENCE,
IMPACT, AND OPPORTUNITIES**

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ABSTRACT

BACKGROUND: Limited health literacy disproportionately affects those with limited English proficiency (LEP). Parents with LEP might rely on their adolescent children to interpret health information. We call this *adolescent health care brokering*. This study uncovers the prevalence of brokering, kinds of tasks, emotional and academic impact, and desired support.

METHODS: We invited 165 students from health classes (in a community in which 29.8% are foreign-born and 53.4% speak another language at home) to complete a survey. We used IBM SPSS to calculate descriptive statistics.

RESULTS: Of the 159 who received parental consent and assented, 54.1% (n=86) assist with healthcare tasks. When brokering, 80.2% (n=69) translate. Most common tasks were talking to a doctor, reading prescriptions, and searching on the Internet. Participants were most confident reading prescriptions and talking to a doctor and least confident finding healthcare services. Among brokers, 29.1% (n=24) missed school; 33.7% did not complete homework. They most wanted to learn about filling out insurance forms and talking to doctors.

CONCLUSIONS: Despite assurances that children are not permitted to interpret, adolescents *are* acting as healthcare brokers. The impact can be academic and emotional. Findings indicate a need for further research and support for adolescents who want to learn about healthcare tasks.

BACKGROUND

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” (p.10).¹ In practice, health literacy includes, but is not limited to, being able to access health care services, analyze relative risks and benefits, calculate dosages, communicate with health care providers, evaluate information for credibility and quality, interpret test results, and locate health information. It also includes knowledge of the body, health behaviors, and the health care system. Being able to perform such tasks and holding such knowledge predicts one’s health

more than age, income, employment status, education level, or race.² In part, this is because individuals who are health literate are better able to comply with prescribed treatment and self-care regimens.³ In contrast, those individuals with poor health literacy have a higher risk of death, more emergency room visits and hospitalizations, and poorer mental health.⁴⁻⁷

Limited health literacy disproportionately affects lower socio-economic and minority groups, particularly those with limited English proficiency (LEP).⁸ In isolation, low health literacy and LEP pose significant barriers to effectively participating in one's health care, but together the effects are magnified.⁹ As one becomes more fluent in the language and the way health communications are presented, one is more likely to seek health care treatment, and take an active role in gaining access to and using information in ways that promote and maintain good health. Being able to understand health information is *integral* to one's health functioning.¹⁰

While not a product of the ability to read and write, health literacy depends on individuals understanding both written and oral communications. Embedded into this assumption is one's ability to read, write, listen, perform basic numeracy skills, think critically, and make decisions.¹⁰ When there are language barriers, meeting this requirement is difficult. To mediate this gap, and per Title VI of the Civil Rights Act, federally funded organizations (including hospitals, health departments, health plans, social service agencies, physicians, etc.) must provide an interpreter for LEP clients. Despite this legislation, Chen, Youdelman, and Brooks describe the implementation of this requirement as a "patchwork quilt" which varies from state to state, language to language, condition to condition, and institution to institution.¹¹

In the case of immigrant families, in which members may have LEP, parents might rely on their adolescent children to interpret health information being shared or needing to be communicated. In this study, we call this *adolescent health care brokering*. In the U.S., the notion of children of non-English speaking parents translating information, while not technically legal, is not new. *Language brokering*, coined by Tse, refers to children acting as linguistic and cultural intermediaries.¹² Katz identifies the translator and uses the term *child brokering* to describe children of immigrants who are socialized in U.S.

schools and interpret both culturally and linguistically for their parents.¹³ While Katz's term does embody children brokering in the health care system, we use the term *adolescent health care brokering* to make it explicitly clear the focus is on adolescents navigating the health care system and advocating for their families, and often themselves, in that system.

Given the likelihood there will always be people with LEP in the U.S. and despite Title VI of the Civil Rights Act, which ensures the right to a medical interpreter, we predict adolescent children of LEP parents will continue to act as healthcare brokers. The purpose of our research was to uncover the prevalence of adolescent healthcare brokering in a high school community, the kinds of healthcare tasks brokered, the emotional experience, academic impact, and desired support. We hope this research will raise awareness of this issue, inspire school health professionals to examine their own schools, and stimulate conversation about how schools can positively support students and their families when there is a language gap in access to healthcare.

METHODS

Participants

With institutional review board approval, 165 students from seven different health education classrooms were invited to participate in the study. These students attend a Midwestern high school in a major metropolitan area. In the town in which the high school resides, 53.4% of the population is Hispanic/Latino, 29.8% are foreign-born persons, and 54.2% speak a language other than English at home. Of the population 25 years of age and older, 29.3% have less than a high school education, and 19.2% live below the poverty level.¹⁴ As stated earlier, lower socioeconomic status, when coupled with LEP and low health literacy, can lead to compounded health outcomes,^{8,13,15} thus making this high school an ideal community on which to focus in this study. The school has an enrollment of 4,579, of which 74.9% are Latino/ Hispanic, 63% are low-income students, and 12.1% are English language learners. The high school is in the bottom 20% of high schools in its state based on state math and reading tests.¹⁶ Though the research is inconclusive regarding the connection between math and health literacy skills, reading ability is connected; therefore, students at this school are at greater risk for poor health

literacy.^{17,18} To participate, students needed to obtain written parental consent and to provide assent.

Participants had the option to skip any question.

Procedure

A health education teacher at the selected high school permitted the researchers to administer the survey (described in the next section) during regularly scheduled class time (four courses in fall 2015 and three courses in spring 2016). Students in this school each have their own Chromebook (a personal laptop), so it was easy to administer the online survey. Parent consent forms were sent home and collected the week prior. Students with parental consent were given the option to assent on the first page of the survey. If students did not have parental consent or did not assent, they were given the time to complete other work. Participants were informed that their responses were kept confidential and the information would be used to tailor the health education curriculum to meet their needs and to identify desired support.

Instruments

An online survey was created to collect data from participants. The first five questions were demographical (age, gender, ethnic/racial groups, and languages spoken at home). We next posed a question intended to identify those who broker from those who do not. If participants responded that they help family members with healthcare tasks, they were asked to identify which ones from a list of the kind of healthcare tasks. This list of tasks was derived from an open-ended survey conducted with students in spring 2015. Participants also had the option to write in other tasks. Next, participants indicated whether or not they translated healthcare task information from English, if they had missed school or were unable to complete homework due to helping with healthcare tasks, and how often these latter events occurred. Next, spring 2016 participants, in a new question not posed in fall 2015, rated their confidence in performing common healthcare tasks. After this question, participants identified emotions they felt from a list of positive and negative emotions selected from the Positive and Negative Affect Scale (PANAS; Watson, Clark, & Tellegen, 1988), an assessment tool used in psychology and sociology to measure feelings. In the final two questions, these participants identified skills from a list of common healthcare

tasks about which they would like to learn more and the types of support they would like to receive.

These types of support also were derived from the open-ended survey in spring 2015.

If participants, after the demographic questions, indicated they did *not* help family members with healthcare tasks, they were bumped to the end of the survey. In future research, these non-brokers also will respond to the same two questions that brokers answered about confidence in performing healthcare tasks (so as to compare broker's responses to non-brokers) and types of skills they would like to learn (as they, too, as future adults, would benefit from learning how to perform common healthcare tasks).

Data Analysis

We used IBM SPSS version 22 to analyze the data using basic descriptive statistics. We excluded cases pairwise when data was missing for a specific analysis.

RESULTS

Demographics

Of the 165 students invited to participate in the study, 160 received parental consent and provided assent. We discarded one student's responses as he/she checked every item when a question invited more than one response and typed questionable items into the "other" boxes. Of the 159 participants, 49.1% (n=78) were male, 49.1% (n=78) were female, 0.6% (n=1) identified as transgender, and 1.3% (n=2) preferred not to answer. Though a sophomore-level health class, ages varied as some students were repeating the course or had transferred from another district. Of the 159 participating, 56% were 14 years old, 18.9% were 15 years old, 17.0% were 16 years old, 6.3% were 17 years old, and 1.9% were 18 years old.

Regarding race/ethnicity, we asked participants first to indicate whether they were Hispanic/Latino or not. Of those responding to this question (n=157), 80.9% (n=127) indicated they were Hispanic/Latino. In the next question, we asked participants with what other racial/ethnic groups they identify. Of the 127 who indicated Hispanic/Latino, 18.9% (n=24) identified one or more other ethnic/racial groups. Similarly, of those 30 participants indicating *not* Hispanic/Latino, 26.6% (n=8) indicated more than one race. Also, six (of the 157 participants) indicated they were multiracial, but did

not indicate their background. This means 38 (24% of 157 responding) participants identified with more than one race or ethnic group. Of those 22 participants indicating *not* Hispanic/Latino and only a single race/ethnic group, 46.6% (n=12; 7.6% of all 157 responding) were Black or African American, 13.7% (n=3; 1.9% of all 157 responding) were Asian, 9.0% (n=2; 1.3% of all 157 responding) were American Indian or Alaskan Native, 9.0% (n=2; 1.3% of all 157 responding) were White, and 13.7% (n=3; 1.9% of all 157 responding) were Other.

Prevalence and Kinds of Adolescent Healthcare Brokering

Of the 159 participants, 54.1% (n=86) indicated they assist family members with healthcare tasks. Table 1 reveals which healthcare tasks were performed most frequently on behalf of family members, with top tasks including talking to the doctor or nurse, reading prescription labels, looking up health information on the internet, talking to the pharmacist, and filling out medical insurance forms. Less common were talking to the insurance company or finding a doctor. When participants performed these healthcare tasks, 80.2% (n=69) translated information from English into their family members' primary language. Of the 159 participants, 76% (n=121) spoke Spanish in addition to English; 18.2% (n=29) spoke English only. Other languages spoken at home (less than 2% each) included Arabic, Creole, Filipino, French, Italian, Indian, Jamaican, sign language, and Tagalog. Six students spoke three or more languages at home.

Emotional Experience of Brokering

With regards to confidence in performing healthcare tasks, participants indicated they were most confident reading prescriptions, talking to a doctor or nurse, preparing for an office visit, and talking to a pharmacist. They were least confident finding healthcare services when uninsured, filling out medical insurance forms, and reading medical bills. Table 2 reveals the degree of confidence in performing common healthcare tasks. Participants responded on a scale of 0 to 4, with 0 being *not confident at all* and 4 being *very confident*. Only spring 2016 participants who indicated they helped with healthcare tasks were presented with this new question after the researchers determined that this data could be valuable.

The emotional experience of performing healthcare tasks for family members varied. Table 3

reveals the number of participants citing each emotion. The most frequently cited negative emotion was *nervous*, and the least cited negative emotions were *angry* and *ashamed*. The most frequently cited positive emotions were *calm* and *confident*. The least cited positive emotions were *excited* and *strong*. Table 4 reveals the net emotional experience. This was calculated by calculating the average of the number of times participants indicated positive and negative emotions. Indicating an emotion felt scored 1 point; not indicating an emotion was scored 0 points. On average, participants cited positive emotions 1.84 times and negative emotions .86 times (n=86). To calculate a net emotion, we subtracted individual's average negative emotion score from their average positive emotion score and derived a net .98 positive score. This means that positive emotions might more often be felt than negative emotions when it comes to performing healthcare tasks.

Academic Impact

It appears helping with healthcare tasks does not go without an academic impact. Of the 86 participants who help with healthcare tasks, 79 responded to the question about academic impact. Of those, 29.1% (n=24) indicated they have missed school to help a family member with a task. Of those missing school, 79% indicated they missed 1-2 classes and 21% indicated they missed 3-4 classes in a typical school year. No one indicated missing more than four classes. Of the same 79 participants, 66.3% indicated helping with healthcare tasks did not hinder their ability to complete homework in a typical school month; however, 27.5% indicated being unable 1-2 times, 3.8% were unable 3-4 times, and 2.6% were unable five or more times.

Desired Support

Among the 86 participants who help with healthcare tasks (and who responded to this question), 80% expressed interest in some type of support. The most popular desired support was a website to ask questions and receive answers about healthcare tasks (32.9%), to obtain healthcare information in English and their family's language (29.5%), or to read information or watch videos about healthcare tasks (21.2%). Also of interest was a during-school (18.2%) or after-school (12.9%) support group. Students were less interested in an online (8.2%) or community (1.2%) support group.

When the participants who help with healthcare tasks were asked about what topics they would like to learn more, some topics were more popular than others. Table 5 reveals these topics in order from most to least. Most popular was learning how to fill out medical insurance forms and how to talk to a doctor. Least popular was finding health services close to home and common prevention medical exams.

DISCUSSION

Prevalence and Kinds of Brokering Performed

Results from this study indicate the majority of adolescents, from this sample, act as healthcare brokers, performing healthcare tasks on behalf of family members and translating from English to their family member's primary language. Despite assurances that children are not permitted to interpret for their parents in a medical setting, more than 62% of the participants who broker indicate they spoke with doctors or nurses on behalf of their family members, a finding similar in a comparable communities.¹⁹ One might have predicted this study's participants to interpret when a family member speaks a language less common in their community (e.g. Arabic, Creole, Filipino), but 76% of the participants spoke Spanish and live in a community in which 53.4% identify as Hispanic/Latino. In other words, even though the participants live in a community where the majority minority speaks Spanish, interpreting services or access to health information in Spanish has not yet met the demand. Or, perhaps, medical professionals find obstacles to using such resources. This finding is consistent with other research indicating general practitioners, due to operational constraints, but against their ideology, sometimes rely on children to interpret.²⁰

Outside of the doctor's office, 57% of the participants who broker indicate they read prescriptions to family members or looked up health information on the Internet. The latter task might also represent a gap between child and parent in technology proficiency; but the former raises concern. Also, talking to pharmacists and filling out medical insurance, though performed less often (43% and 32.6% of brokers), seem to be activities that could have great medical or financial consequences if not performed correctly. This could be perceived as a great burden for a 14-15 year old adolescent, who may not have had any training in doing either task.

Emotional Experience

The emotional experience of brokering was measured in terms of confidence and then positive and negative emotions. Results indicate participants were most confident in reading prescriptions and talking to a doctor or nurse, but given the scale was 0-4 with being *very confident*, an average score of 3.05 for each task suggests participants have room to improve. This finding, coupled with the prevalence of healthcare brokering, points to the need for health education curriculum to include commonly performed healthcare tasks. Currently, such tasks are not a main content area promoted by the CDC's Health Education Curriculum Analysis Tool (HECAT),²¹ but they do align with several of National Health Education Standards (NHES),²² particularly NHES 3 and 8, and possibly NHES 4 and 7. These four standards are as follows:

3. Students will demonstrate the ability to access valid information, products, and services to enhance health

4. Students will demonstrate the ability to use interpersonal communication skills to enhance health and avoid or reduce health risks.

7. Students will demonstrate the ability to practice health-enhancing behaviors and avoid or reduce health risks.

8. Students will demonstrate the ability to advocate for personal, family, and community health.

School health educators who align curriculum with the NHES could deliver instruction that develops students' functional health knowledge about and skills related to the most commonly performed healthcare tasks.

In addition to confidence, we investigated participant's reported positive and negative emotions associated with healthcare brokering. Consistent with past research,²³ the results indicated a mixture of positive and negative emotions. Overall, participants reported more positive emotions than negative emotions, a finding concurrent with Weisskirch who found young people generally experienced positive feelings when interpreting.²⁴ Despite the skew towards positive, the negative emotions should not be ignored. Previous research found among adolescent who act as language brokers, those who reported

more negative feelings were at greater risk for acculturation stress, and in turn, alcohol and marijuana use.²⁵ That research also found efficacy and perceived norms (specifically whether or not their peers also were brokering) appeared to counteract reported stress. Those findings further support the need for health education that includes content on and skill development in commonly performed healthcare tasks. Also, it suggests open discussions among peers who act as healthcare brokers might reduce some of the negative emotions associated with brokering.

Academic Impact

A previous study found the amount of brokering is inversely associated with academic performance, feelings of ethnic belonging, and substance use.²⁶ Lower levels of brokering were associated with greater academic performance, and higher levels were associated with the opposite. These findings suggest the extent of brokering matters. In the current study, almost one-third of participants who broker miss some school, but no more than four times per year, to help with healthcare tasks. However, worth noting is the number of students who indicate they were unable to complete homework or study due to brokering. More than one third indicated being unable to do so, with some indicating five or more instances in a month. This suggests adolescents who broker might have to choose between school and helping family members.

Desired Support

While less interested in a support group, approximately one-third of the participants wanted a website where they could ask questions about healthcare tasks, obtain healthcare information in English and their family's language, and/or read about or watch videos about healthcare tasks. Exposing adolescents to credible sources of health information might help them to overcome or to minimize some of the challenges associated with looking for health information.¹⁹ Currently, popular health information websites such as Medlineplus and Mayo Clinic also offer information in Spanish, but this does not resolve the situation for other languages. Google Translate might offer an option to users searching online for health information, but it is less helpful for offline healthcare tasks such as reading prescription labels or filling out health insurance forms.

Assuming there will always be adolescents who will perform healthcare tasks for their family members and interpret while doing so, and given these adolescents will soon become young adults responsible for their own health, there is value in health education curriculum that bestows knowledge and skills about commonly performed and critical healthcare tasks. This study's participants indicated interest in learning more about several tasks including talking to a doctor or nurse, reading prescription labels, and filling out medical insurance forms. As mentioned earlier, such content could align with the NHES and be included into health education curriculum.

Limitations

One limitation of this study was its sample size. A larger sample size would provide greater statistical power; a sample from another community will allow us to better generalize our results. Also, the participants were largely Hispanic. Adolescents who speak languages other than Spanish, which is increasingly becoming a second language in the U.S., might more often act as healthcare brokers because there are fewer interpretation or bilingual healthcare information resources available to their parents. Another limitation pertains to the accuracy of information collected. It is possible that some participants did not identify themselves as healthcare brokers or limited they shared for fear or shame associated with the act or with revealing their family members' LEP status.

Conclusions

Being able to understand health information is *integral* to one's health functioning.¹⁰ In the case of immigrant families, parents with LEP might rely on their adolescent children to interpret health information. In this study, we call this act *adolescent health care brokering*. The purpose of our research was to uncover the prevalence of adolescent healthcare brokering in a selected community, the kinds of healthcare tasks brokered, the emotional experience, the academic impact, and desired support. Findings indicated the majority of participants, who were high school students, were helping family members with healthcare tasks and most of them were interpreting while doing so. Feelings about brokering were mostly positive, however there is room for growth in confidence when it comes to performing healthcare tasks. Also, some participants missed school and/or were unable to complete homework or study because

there were brokering. Finally, participants indicated an interest in learning more about commonly performed healthcare tasks and a website where they could obtain support in the form of information. Further research into the phenomenon we call healthcare brokering is warranted as well as means to support those who do it.

IMPLICATIONS FOR SCHOOL HEALTH

Our hope is this research will raise awareness about adolescent healthcare brokering, inspire school health professionals to examine their own schools, and stimulate conversation about how to positively support students and their families when there is a language gap in access to healthcare in their community. The researchers and teacher in this study are currently working with the Nemours Foundation to implement, with health education students, a health literacy curriculum the Foundation is piloting at the time this article was written. This curriculum may soon be available to a wider audience. For those creating their own curriculum, school health professionals and educators could work together and use the NHES as a guide to develop instruction that provides students with information about and opportunities to practice common and/or critical healthcare tasks. Even those students who do not broker will benefit as they, too, will soon become adults who need to manage their own health. Also, school health professionals can act as a resource for students who broker by identifying and providing information about services in the community to which these adolescents and their families may turn when parents have LEP or low health literacy skills. Finally, school health professionals could work with their school or district's administration team to identify the prevalence and kinds of adolescent healthcare brokering, the emotional experience, the academic impact, and the desired support. [Readers can obtain this study's evaluation tool by contacting the lead author, Dr. Jennifer Banas, at j-banas@neiu.edu]. The language one's family speaks should not have to be an obstacle to optimal health and school health professionals can help to reduce this disparity.

Human Subjects Approval Statement

The study was approved by Northeastern Illinois University's Office of Research and Sponsored

Programs. The participating school district inspected study protocols to ensure compliance with human subjects and research regulations.

Table 1. Healthcare Brokering Tasks Most Frequently Performed on Behalf of Family Members

Healthcare brokering task	Frequency of times cited (N=86) Number (%)
Talking to their doctor or nurse	54 (62.8)
Reading their prescriptions	49 (57.0)
Looking up health info on the internet	49 (57.0)
Talking to the pharmacist	37 (43.0)
Filling out medical insurance forms	28 (32.6)
Talking to the health insurance company	9 (10.5)
Finding a doctor	8 (9.3)

Table 2. Confidence in Performing Healthcare Tasks

Healthcare task	N	Mean	SD	SE
Read prescriptions	44	3.05	.861	.130
Talk to a doctor or nurse	44	3.05	.746	.112
Prepare for a doctor's visit	44	2.86	.979	.148
Talk to a pharmacist	44	2.86	.878	.132
Find good health info on the internet	44	2.66	.805	.121
Find a doctor	44	2.61	.993	.150
Find healthcare services close to home	44	2.61	.868	.131
Make a doctor's appointment	44	2.61	.993	.150

Read a medical bill	44	2.32	.934	.141
Fill out medical insurance forms	44	2.27	.872	.132
Find healthcare services when you don't have health insurance	44	2.05	.861	.130

Table 3. Frequency of Emotions Experienced

Emotion	Frequency cited (N=86)
Negative emotions	
Nervous	38 (44.2)
Stressed	16 (18.6)
Scared	10 (11.6)
Sad	6 (7)
Alone	2 (2.3)
Angry	1 (1.2)
Ashamed	1 (1.2)
Positive emotions	
Calm	44 (51.2)
Confident	37 (43.0)
Determined	23 (26.7)
Proud	20 (23.3)
Happy	18 (20.9)
Strong	11 (12.8)
Excited	5 (5.8)

Table 4. Net Emotional Experience

Emotion	n	Range	M	SD	VAR
Negative emotions	86	0-5	.86	1.086	1.180
Positive emotions	86	0-7	1.84	1.486	2.208
Net emotions	86	-4-7	.98	2.041	4.164

Table 5. Healthcare Task Topics about Which Participants Would Like to Learn More

Topic	Frequency cited (N=85) Number (%)
How to fill out medical insurance forms	35 (41.2)
How to talk to a doctor or nurse about a health problem/question	32 (37.6)
Best websites to look up health conditions	27 (31.8)
How to read legal documents about health decisions	27 (31.8)
How to read a medical bill	27 (31.8)
How to find good health information on the internet	25 (29.4)
Healthcare terms/words	24 (28.2)
How to make a doctor's appointment	24 (28.2)
How to prepare for a doctor's visit and what to bring	21 (24.7)
Healthcare terms in both English and language your family members speak	23 (27.1)
Legal terms in both English and language your family members speak	20 (23.5)
How to talk to the health insurance company	19 (22.4)
How to help them make healthy food choices	19 (22.4)
Where to go for healthcare when you don't have health insurance	18 (21.2)
How to talk to a pharmacist	17 (20.0)

How to read prescriptions	17 (20.0)
How to find a doctor or hospital	15 (17.6)
Find healthcare services close to your home	13 (15.3)
Common prevention medical exams	11 (12.9)
Nothing	12 (14.1)

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