Achieving social justice through school health: Understanding and supporting the adolescent healthcare broker

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Health Literacy

“Cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information...which promotes and maintains good health.” (WHO, 2012)
Barriers to Health Literacy

Health literacy depends on individuals being able to understand written and oral communication (Berkman et al., 2011).

When there are language barriers, meeting this requirement is difficult.
Limited English Proficient (LEP) Americans

60 Million Americans speak more than one language

350 Languages

25 Million require language assistance

States with the largest LEP populations:
- California (6.8 million)
- Texas (3.4 million)
- New York (2.5 million)
- Florida (2.1 million)
- Illinois (1.1 million)

Thor & Ceja, 2015, Whitehouse.gov
And so begets....

The Adolescent Health Care Broker
Adolescent Health Care

Brokering

When an adolescent acts as an interpreter for family members who speak a language other than the language in which health information is shared or needing to be received.

Examples:
- communicating with a doctor, nurse, or pharmacist
- reading prescription labels
- searching for health information on the Internet
- locating health services
- filling out medical forms or legal documents.
Background

Title VI of the Civil Rights Act assures a medical interpreter for those with LEP; however, it is not always possible or desirable to access these services.
Project Aims

Use mixed-methods, transformative research approach rooted in grounded theory to:

1) document the prevalence and kinds of adolescent healthcare brokering within a target, underserved population.

2) understand the emotional experience of brokering

3) uncover existing supports and desired training.

With this information, our aims were to form community partnerships, engage families, and seek funding to provide appropriate school-based training and support.
## Community/school demographics

**Waukegan**
- 41.3% is Latino
- 25.7% foreign-born
- 45.2% speak a language other than English at home.
- Of pop. 25yrs+, 25.6% have < HS degree
- 14.8% live below the poverty level.

(U.S. Census, 2010)

**Waukegan H.S.**
- Enrollment - 4,672
- Hispanic – 76.7%
- Low income – 47.4%
- ELL– 13.3%
- Graduation rate:
  - 4 years – 75%
  - 5 years – 81%

(Illinois Report Card, 2016)
Why mixed-methods?

Narratives complement, extend, and humanize otherwise impersonal quantitative data (Sweetman, Badiee, & Creswell, 2010).

Combined with an advocacy lens, increasingly it’s 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.
Why grounded theory?

Grounded theory includes researchers building theories as they progress through stages of the data analysis (Glaser & Strauss, 1967).

There is compatibility between grounded theory and social justice because of the need to be critically self-reflective and to provide for reciprocal benefits (Charmaz, 2006).

To do this, Charmaz proposes researchers ask the following:

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

With IRB and school approval:

• Quantitative surveys were administered online during health education class

• Focus groups were conducted in a private room during health education class time

Parental consent and participant assent was required for both data collection methods.
Study Population

Study population: 244 students enrolled into 1 teacher’s health education classes over 3 semesters.

Gender:
- Male (48.3%)
- Female (48.7%)
- NA (2.6%)
- Transgender (0.4%)

Racial/Ethnic:
- Latino/Hispanic – 82.1%
- Speak Spanish in addition to English at home – 76.9%
Survey Results

Prevalence of brokering:

• 57.5% (n=137) of 238 surveyed perform healthcare tasks for family

• 81.7% (n=112) of those 137 participants who perform healthcare tasks for family do so because of language barriers.
Survey Results

Tasks performed:

<table>
<thead>
<tr>
<th>Healthcare brokering task</th>
<th>Times cited (N=137)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reading their prescriptions</td>
<td>89 (57.0)</td>
</tr>
<tr>
<td>Talking to their doctor or nurse</td>
<td>87 (63.5)</td>
</tr>
<tr>
<td>Looking up health info on the internet</td>
<td>72 (52.6)</td>
</tr>
<tr>
<td>Filling out medical insurance forms</td>
<td>51 (37.2)</td>
</tr>
<tr>
<td>Talking to the pharmacist</td>
<td>37 (46.7)</td>
</tr>
</tbody>
</table>
Survey Results:

Emotional experience and academic consequences

Most common feelings associated with brokering:

Negative
- nervous (44.5%)
- stressed (18.2%)
- Scared (12.4%)

Positive
- calm (50.4%)
- confident (43.1%)
- determined (24.5%)

Each indication of an emotion was scored as 1 point. Max score = 7

Avg. negative emotional score = .88
Avg. positive emotional score = 1.87
Survey Results

Of those who broker, 32% (n=44) missed school to help family. In a typical year...
  o 77% missed 1-2 classes
  o 21% missed 3 or more classes

For those who broker, 32% (n = 44) helping sometimes hindered their ability to complete homework. In a typical school month...
  o 28% indicated being unable 1-2 times
  o 6% were unable 3 or more times
## Survey Results

### Desired training:

<table>
<thead>
<tr>
<th>Topics about which they would like to learn</th>
<th>(N=137) # (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How to talk to doctor/nurse about health problems</td>
<td>58 (42.6)</td>
</tr>
<tr>
<td>How to fill out medical insurance forms</td>
<td>55 (40.4)</td>
</tr>
<tr>
<td>How to read a medical bill</td>
<td>45 (33.1)</td>
</tr>
<tr>
<td>Healthcare terms/words</td>
<td>45 (33.1)</td>
</tr>
<tr>
<td>How to make a doctor’s appointment</td>
<td>44 (32.4)</td>
</tr>
<tr>
<td>How to prepare for a doctor’s visit; what to bring</td>
<td>44 (32.4)</td>
</tr>
<tr>
<td>How to find good health info on the internet</td>
<td>43 (31.6)</td>
</tr>
<tr>
<td>How to read legal documents for health decisions</td>
<td>41 (30.1)</td>
</tr>
<tr>
<td>How to talk to the health insurance company</td>
<td>40 (29.4)</td>
</tr>
<tr>
<td>Best websites to look up health conditions</td>
<td>39 (28.7)</td>
</tr>
</tbody>
</table>
Focus Group Results (n = 11)

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.
Theme A: The kinds of tasks brokered and their complexity varied broadly.

• “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.”
• “…my uncle, he had rocks in his stomach, so I had to translate to him what they were going to do.”
• “I’ve read the directions on insulin shots and explained how it works.”
• “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.”
• “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.”
Theme B: The emotional experience was dichotomous.

Negative

- Felt “…anxiety because you might say something wrong. Like explaining it wrong.” “…my uncle, he had rocks in his stomach, so I had to translate to him what they were going to do.”
- “I kinda worry about it after[wards]. Cuz like if [the doctor] leaves and [my parents] are kinda like ‘I don’t understand what’s happening,’ …I worry.”

Positive

- “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.”
- Feels sense of accomplishment. “Every time I go I learn something new like a better word to use.”
Theme C: There was inconsistent access to interpreting services and translated materials

On making a doctor’s appointment: “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.”

At the doctor’s office: “There was no one that could interpret what my mom was saying.”

At the pharmacy: “When we went to the store....and they need their medical prescription, I have to ask.

In contrast, at another pharmacy: “Most of the time, people speak Spanish now at pharmacists everywhere.”
Theme D: There was a lack of formal support for adolescents who broker

On whom do you rely?

• “It depends on who I go with or who I’m helping. If I go with my uncles, I’ve got my cousins.”
• One participant indicated she was an only child, so she doesn’t have any siblings to help her.
• “My sisters. We know different types of Spanish. I know bigger words, but they know basic words I don’t know.”

Sometimes the health professionals try to help...

• “I used to go to with [my aunt] since she didn’t understand the machines. They kinda simplified it for me.”
So what’s next?
Provide education and training

The Nemours Foundation’s health education curriculum
Seek funding

Sought and received a $25,000 grant from the Healthcare Foundation of Northern Lake County (IL) to:

- **Curricular:** To enhance the health literacy curriculum to be more personally relevant to WHS students, to engage students' families in health literacy, to promote careers in health, and to identify local/regional pathways to those careers.

- **Research:** Assess short- and long-term impact of the enhanced curriculum

- **Advocacy:** Form community partnerships

- **Advocacy:** Disseminate findings with professional and local communities
Contact us for....

• Published research articles in the American Journal of School Health and the Journal of Community Health

• Information about the Nemours Foundation’s Navigating the Health Care curriculum

• Anything that was not answered for you today

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