

Health Insurance Literacy Perceptions and the Needs of a Working-Class Community

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ABSTRACT

Background: Despite increases in the number of insured Americans, consumers continue to face barriers in accessing care. Low levels of health insurance literacy (HIL) are associated with suboptimal use of health insurance coverage. There remains a need to further contextualize the relationship between HIL and access to care, especially among insured working-class people. **Objective:** This study was conducted to understand the pathways through which HIL affects health care decision-making and access to care in an urban working-class population. **Methods:** Using a qualitative descriptive approach, we conducted five focus groups with 45 adult residents of South Louisville, Kentucky. The questions explored participants' experiences of insurance enrollment, use, and health care system navigation, as well as their perceptions and needs regarding accessing health insurance information. Using inductive thematic analysis, transcripts were open coded independently by team members, a focused coding framework was agreed upon, and emergent themes were identified through constant comparison techniques. **Key Results:** Most participants placed high value on their insurance, considering it the most important benefit employers offer. Despite having adequate HIL, most participants expressed frustration with the amount of time and effort they spent to determine the best insurance plan, obtain covered health services, and settle claims, often with ineffective results. Despite having insurance, cost considerations influenced many participants' decisions to accept certain tests or treatments, in some cases resulting in delayed or foregone care. **Conclusions:** The findings of this qualitative study indicate that obtaining health care is strongly influenced both by the individual context of HIL knowledge, experience, and life circumstances, and by the structural context of the complex, bureaucratic, and costly health care system. Interventions to improve HIL should include practical examples and real-life scenarios, because HIL gained from experiential narratives was the most useful in navigating the health care system. [*HLRP: Health Literacy Research and Practice*. 2022;6(2):e61–e69.]

Plain Language Summary: By conducting focus groups with a working-class population, this study contextualizes the pathways through which HIL affects consumers' health care decision-making and access to care. Findings demonstrate that obtaining health care is strongly influenced both by the individual context of HIL knowledge, experience, and life circumstances, and by the structural context of the complex, bureaucratic, and costly health care system.

A major goal of health insurance expansion is to increase access to care. However, rapid changes to the American health care landscape have not been accompanied by large scale efforts to improve health insurance literacy (HIL) and teach the skills necessary to navigate the health care delivery system (Edward et al., 2019; Quincy, 2012a). The passage of the Affordable Care Act (Patient Protection and Affordable Care Act, 2010) extended coverage to approximately 22.8 million Americans (Carman

et al., 2015) and Kentucky was among the first states to expand Medicaid eligibility and establish a state-based health insurance exchange (Buchino et al., 2016; Creel & Buchino, 2016). This resulted in the largest state decline in the uninsured rate in the nation between 2013 and 2016 (Witters, 2017), reducing disparities in unmet needs due to costs (Benitez et al., 2018).

HIL is the “knowledge, ability, and confidence to find and evaluate information about health plans, select the best plan

for. . . [one's]. . . financial and health circumstances, and use the plan once enrolled" (Quincy, 2012a). Notably, health literacy, numeracy, and financial literacy are necessary components of HIL (Kim et al., 2013). A large nationally representative survey found that one-half of adults were not confident in using health insurance effectively (Edward et al., 2019). Another representative survey found that although about 70% understood basic insurance terms, only 16% could calculate out-of-pocket costs (Norton et al., 2014). Both surveys found disproportionately lower HIL among young adults, uninsured, and those with lower income and education (Edward et al., 2019; Norton et al., 2014).

Studies have shown that low HIL may contribute to delayed or foregone care, even among the insured (Long et al., 2014; Morgan et al., 2008; Tipirneni et al., 2018). Limited HIL is associated with higher uninsured rates, suboptimal selection and use of health insurance coverage, lower uptake of preventive services, more frequent emergency department visits, delayed or foregone care, and poorer perception of overall health (Barnes et al., 2015; Hoerl et al., 2017; Loewenstein et al., 2013; Long et al., 2014; Mayo et al., 2016; Morgan et al., 2008; Paez et al., 2014; Quincy, 2012a, 2012b; Tipirneni et al., 2018). There remains a gap in the literature about the processes through which HIL influences these outcomes in various contexts. Therefore, further contextualization is needed about the association between HIL and access to care.

The aim of this qualitative study is to understand how HIL affects consumers' health care decision-making and access to care. It explores the health insurance experiences of the working-class population of South Louisville, Kentucky, and serves as a comparison to an HIL study conducted in

the predominantly African American community of West Louisville, Kentucky (Ali et al., 2018; Muvuka et al., 2020).

South Louisville is a racially and ethnically diverse, and predominantly working-class community that spans seven neighborhoods and eight zip codes (Kelly Pryor et al., 2017). The residents are 76% White, with a median household income of \$45,559 and 89% have insurance coverage (U.S. Census Bureau, 2016). Although South Louisville does not have the poorest health indicators in the city, there are troubling disparities between these neighborhoods and Louisville Metro as a whole. South Louisville's life expectancy of 75.5 years is below the Metro average of 76.8 years, and well below the life expectancies in the city's wealthiest areas, which range from 78 to 82 years (Kelly Pryor et al., 2017).

METHODS

Using a qualitative descriptive approach, five focus groups were conducted with adult South Louisville residents and one individual interview was conducted in American Sign Language (ASL). To ensure access to residents in all five South Louisville neighborhoods (Fairdale, Valley Station, Shively, Iroquois, and Okolona), separate convenience sampling was undertaken within each neighborhood and focus groups were held at publicly accessible locations in each neighborhood. Participants were recruited through flyers at community centers, churches, libraries, and businesses; phone outreach to local organizations and leaders; and word of mouth, with the stated purpose of discussing their health insurance experiences and information preferences. Participants were offered a \$20 gift card as compensation. The study was approved by the Institutional Review Board at the University of Louisville.

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Grants: This study was supported by the Commonwealth Institute of Kentucky and KentuckyOne Health.

Disclosure: The authors have no relevant financial relationships to disclose.

Received: October 6, 2020; Accepted: March 4, 2021

doi:10.3928/24748307-20220309-01

The focus groups and interview, each lasting between 60 and 90 minutes, were facilitated by the authors (R.K., R.M.C., M.H.Y., N.A., B.M.), audio recorded, and transcribed verbatim. Using a semi-structured approach, the facilitator guided discussion of each focus group to explore open-ended questions about participants' experiences, perceptions, and needs relating to enrollment and use; health care system navigation; health insurance information-seeking; barriers and enablers to accessing insurance information; and trusted and desirable information delivery modalities.

Transcripts were verified, anonymized, and imported into a web-based data analysis software (Dedoose, Version 7.0.23). Inductive thematic analysis was used to identify emergent themes and subthemes within the data (Braun & Clarke, 2006). Team members open-coded transcripts independently, followed by adjudication and agreement upon a focused coding framework. After focused coding of one-third of the transcripts, an intercoder reliability test was conducted. The results indicated good agreement (Cohen's Kappa 85%). Focused coding was then applied to the remaining transcripts.

Participants completed a brief confidential, written survey with validated measures on self-reported demographics, health status, health coverage, and health care access to characterize the sample. Survey data were analyzed using descriptive statistics in IBM SPSS Statistics 24[®].

RESULTS

Forty-four residents participated in focus groups and one individual was interviewed using an ASL interpreter. Participants' ages ranged from 22 to 82 years, but more than two-thirds were age 55 years or older. The focus groups had an average of 9 participants each, within the best practice range of 6 to 12 (Krueger, 2014; Morgan, 2018). Most participants were female (73%) and White (71%). Only 9% of respondents had less than a high school education, whereas 20% had college degrees; the majority (71%) had a high school diploma or some years of college/technical school. Most participants (73%) were either employed/self-employed or retired. The participants' mean annual household income was \$46,543 (standard deviation: \$17,635; missing = 9). Nearly all participants (96%) reported currently having health insurance coverage, with 40% covered by private insurance (either employer-sponsored insurance [ESI] or purchased through the health care exchange), 31% by Medicare, 13% by Medicaid, and 11% by Veterans or TRICARE insurance. In the past two

years, 22% had changed their health insurance. Most participants (82%) described their general health status as good, very good, or excellent. See **Table 1** for demographics and participant health insurance characteristics.

The qualitative themes presented below fall into four overarching domains (**Figure 1**): the health care system's structural context (complexity, costs); the individual context (HIL knowledge, experience, life transitions); the points at which these contexts intersect (insurance enrollment, accessing health care services); and how health care reform, resources, and support may reduce HIL barriers and lead to more optimal coverage and affordable care. Also represented in **Figure 1** are data from the participants on the emotions that consumers experience while enrolling in health insurance and accessing health care, specifically stress, anxiety, mistrust, and frustration.

STRUCTURAL CONTEXT

Complex, Bureaucratic, and Error-Prone Health Care System

"I don't trust none of them. I don't, because they make it too complicated, it doesn't need to be that way."
—Fairdale participant

Participants found the health care system generally—and health insurance specifically—complex and confusing to navigate. Systemic complexity was considered unnecessary or even intentional. Experiences with health care bureaucracy led to fear and mistrust. The complexity affected consumers' ability to understand their health insurance's terms and calculate health care costs. For example, one consumer stated:

I've met my deductible... the out-of-pocket is what I'm working on now, and still ain't met that. ...Why don't they just combine both of those, the out-of-pocket and the deductible, and make it just one? It is so confusing. —Okolona participant

Participants gave examples of how systemic complexity led to bureaucratic errors, often related to billing. Examples included denials of valid claims and billing for medical supplies not received. Participants described feeling caught between providers and insurers, often bearing responsibility for the bill until the problem was resolved:

I recently had some bills that were denied by the insurance company because of something the doctor didn't word right. You kind of get caught in the middle of that. So, insurance companies let you know, 'We're going back to the doctor to tell them to send us more information.' In the meantime, the doctor's office is sending me 100% of the bill. . .It's real frustrating. The billing is a challenge. —Okolona participant

TABLE 1
Demographics and Insurance Characteristics of Participants (N = 45)

Characteristic	n (%)
Female	33 (73)
Male	12 (27)
Age (years)	
20-40	5 (11)
41-54	9 (20)
55-64	19 (42)
65 and older	12 (27)
Race/ethnicity	
White	32 (71.1)
Black or African American	12 (26.7)
American Indian or Alaska Native	1 (2.2)
Marital status	
Married or partnered	23 (51.1)
Divorced or separated	8 (17.8)
Widowed	7 (15.6)
Never married	7 (15.6)
Employment status ^a	
Employed or self-employed	20 (45.4)
Retired	12 (27.3)
Unable to work	6 (13.6)
Homemaker	3 (6.8)
Out of work	3 (6.8)
Highest education completed	
Grades 1-8 (elementary/middle school)	2 (4.4)
Grades 9-11 (some high school)	2 (4.4)
Grade 12 or GED (high school graduate)	18 (40)
College 1-3 years (some college or technical school)	14 (31.1)
College 4 years (college graduate)	3 (6.7)
Graduate school (advance degree)	6 (13.3)
Have health insurance	43 (95.6)
Type of insurance	
Private insurance/ employer sponsored insurance	18 (40)
Medicare	14 (31.1)
Medicaid	6 (13.3)
Tricare	5 (11.1)
None	2 (4.4)
Length of time covered by current health insurance	
Less than 1 year	4 (8.9)
1-2 years	10 (22.2)
More than 2 years	29 (64.4)
None	2 (4.4)
Changed insurance in past 2 years	
Yes	10 (22.2)
No	35 (77.8)
Have primary care provider	
Yes	41 (91.1)
No	4 (8.9)

Participants discussed meticulously comparing bills and insurance paperwork to resolve discrepancies, which required a sophisticated understanding of the system, time, effort, and persistence.

Insurance and Health Care Are Necessary, But Costs Are High and Unpredictable

A major theme discussed across all focus groups was the high and unpredictable cost of health insurance and health care. Although participants valued health insurance because it protected them from catastrophic emergency costs, some participants questioned its everyday utility (“It seems to me the main reason for health insurance is if there is an emergency. . .because it really doesn’t do much. It might do some.” —Shively participant). Some called for comprehensive reform (“Health insurance as a whole just needs to be rethought in this country.” —Okolona participant).

Participants described surprise bills for costs that they thought would—or should—be covered. They discussed the large proportion of their income spent on insurance, which made unexpected out-of-pocket costs particularly frustrating (“My husband and I have [a plan with] a \$4,000 deductible and then they talk about some other [cost]. . .it’s like, well, have I not paid enough already?” —Iroquois participant). Cost considerations often resulted in delayed or foregone care, even for those with insurance (“There have been times when we cannot afford to go to a specialist

because we don't have the copay."
—Okolona participant).

INDIVIDUAL CONTEXT
Health Insurance Literacy:
Knowledge and Application

Most participants had a basic understanding of health insurance, including concepts such as copays, deductibles, premiums, and provider networks. Nevertheless, they had trouble applying the concepts to their own situation to make an informed decision. As one participant elaborated:

Define understand. Because I have a basic understanding, enough to know what I need to know to use it. The confusing part for me is like when it is open enrollment time, and they're like, 'Here's plan A, B, C, D,' and trying to figure out which level of coverage is going to be best for me. —Valley Station participant

Problems with HIL emerged both when consumers used their plans and changed to new plans. Participants described not fully understanding their plan's details. Sometimes, they did not know if they made the right insurance coverage decision until they had a major medical issue ("We found out when we had this accident that the part B is something he should have had." —Fairdale participant). They found anticipating out-of-pocket expenses especially difficult.

Participants who claimed to be more comfortable with HIL concepts gained their knowledge by working in the healthcare field or by navigating insurance for themselves or a loved one. Some studied insurance documents or sought in-person assistance, but they noted this was time consuming and often frustrating and expressed empathy and concern for those with less knowledge. All participants recognized an acute need for more personalized and accessible health insurance information.

Socioeconomic Status, Employment, and Life Transitions

Participants' socioeconomic status, including their financial circumstances, employment status, and major life transitions, affected their health care coverage. Despite having health insurance, participants in each focus group described fear and anxiety about being uninsured. Uninsured participants coped with these feelings by "trying not to think about it," and hoping they would not need medical care. Expensive costs were said to take a higher toll on "us South End" or "middle class" people.

TABLE 1 (CONTINUED)
Demographics and Insurance Characteristics of Participants (N = 45)

Characteristic	n (%)
Last visit to health care provider	
Within the past year	39 (86.7)
Within the past 2 years	1 (2.2)
5 or more years	4 (8.9)
Never	1 (2.2)
General health status	
Excellent	6 (13.3)
Very good	9 (20)
Good	22 (48.9)
Fair	7 (15.6)
Poor	1 (2.2)

Note. GED = General Educational Development.
*Missing 1 response.

As the most common type of coverage for the participants, ESI was the most frequently discussed. Most participants with ESI valued their coverage and described it as one of the most important benefits employers offer. Indeed, individuals' decisions about employment were often linked to concerns about coverage. Some selected jobs solely for their health insurance benefits.

Look for the health insurance. Make sure that you check that, because if you've got a job that pays good, but you don't have very good health insurance, you're not going to make that much money. —Valley Station participant

Participants usually kept the same insurance plans over time; they faced difficulty when they were required to change their coverage after a major life event (e.g., changing or losing a job, retiring, or becoming disabled). Transitioning coverage was confusing, even for consumers who understood their previous plan. Consumers needed strategies to understand and navigate their new plan at these transition points. Many participants found Medicare especially confusing because it is structured differently than private insurance ("I had to change my insurance to Medicare. . .that was a whole new ballgame. What was this? [laughs]" —Okolona participant).

Several participants were caught in coverage gaps. For example, low-income younger people found that slight increases in pay caused them to churn between cost-free Medicaid coverage and either expensive ESI (if available) or becoming uninsured due to unaffordability. Older participants described being not yet eligible for Medicare but facing higher premiums and more health problems as they aged. Some delayed their retirement until they became Medicare eligible ("That's the reason I continue to work." —Okolona participant).

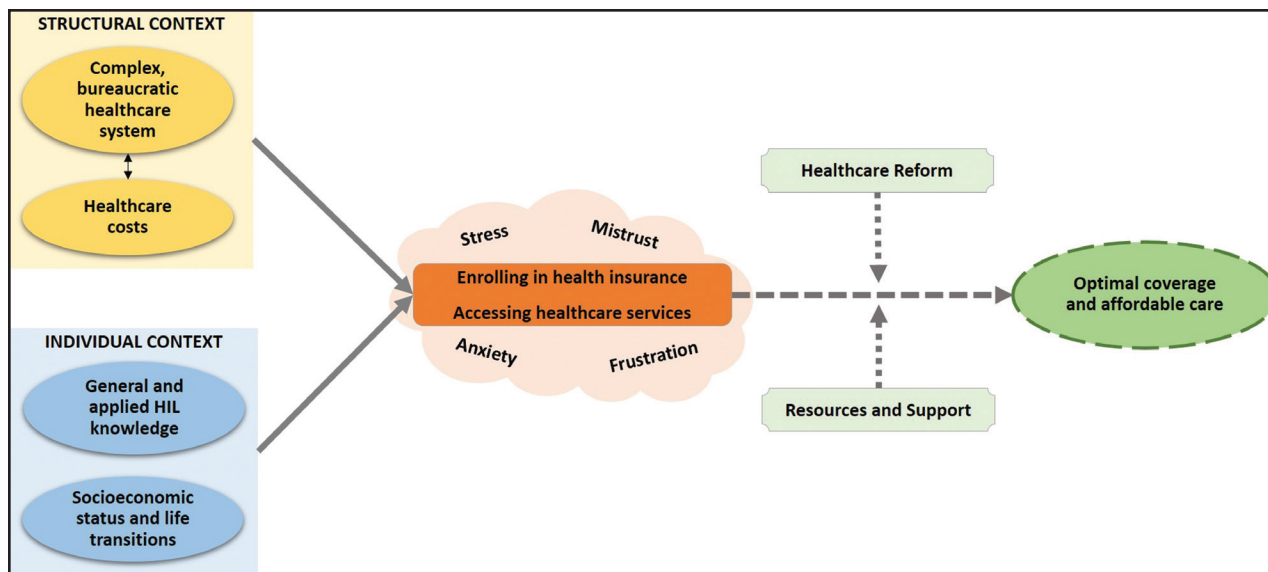


Figure 1. Model developed from inductive thematic analysis shows how health insurance literacy (HIL) interacts with other individual and structural contexts to affect consumers experience when obtaining health care.

INTERACTION WITH THE HEALTH CARE SYSTEM

Enrolling in Health Insurance

One major task requiring HIL was selecting and enrolling in an insurance plan for themselves or their household. Participants reported difficulty understanding plan details, gathering household health and financial information, and making a good decision in the time allotted to open enrollment. For households with multiple earners, different open enrollment periods made it difficult to compare options and make informed decisions. Many described negative emotions during enrollment such as feeling “confused,” “lost,” and “stressed.”

When comparison shopping, plans were primarily selected based on cost, but also provider network and their family’s health needs (“I try to figure out what I can pay a month, what I can pay a year, how often I go to the doctor’s office. Can I go from state to state?” —Okolona participant). Attempting to anticipate the future while selecting the “right plan” provoked anxiety (“Will I need anything during the coming year? You can’t foretell any sort of injury or illness or sickness that might go on.” —Fairdale participant). The result was exasperation; some gave up trying to fully understand their insurance options (“You try to understand it, but at some point, you just have to go with something” —Fairdale participant).

Accessing Health Care Services

Participants described their interactions with the health care system. Specifically, they discussed their decision-making about when to seek health care, their knowledge and strategies related to accessing care, and barriers they experienced. Some

participants did not allow costs to influence their health care decision-making (“Health is too important; you’ll work out the money.” —Okolona participant). However, many delayed seeking health care services due to high co-pays and unpredictable medical bills. According to a participant with ESI:

We try to truly avoid going to the doctor, and at our age, we really should be going to the doctor. But we don’t. Unless you’re really feeling like you’re going to die. . .It’s a shame that we’re in that mindset that we feel like we can’t go. —Valley Station participant

Anticipating high costs also influenced decision-making about accepting certain tests and treatments, regardless of provider recommendations:

I have to sit there and say, you know, ‘do I need to do that?’ It used to be whatever they said I did, but I financially can’t do that anymore, you know, because it’s so costly. —Iroquois participant

Some participants reported that their health care providers did not know if insurance covered the tests or treatments they ordered, or how much it would cost:

[The doctor says] “I’m giving you this shot.”

[I say] “Is it covered?”

[The doctor says] “I don’t know. We can check.”

Then they still don’t know. That’s why I say, “if it’s not covered, I don’t want it!” (—Fairdale participant)

Drawing on their experiences, participants shared strategies for navigating the complex and expensive health care system. For example, one participant emphasized investigating whether the service is covered by insurance before agreeing to the treatment (“It’s a conversation you have to have at the beginning, at the start of the appointment. Am I covered for

this?” —Fairdale participant). Another described how, with persistence, she had navigated a lower drug price through the manufacturer. Determination was considered an important component of success.

Many described a lack of trust toward health insurance companies, providers, and the health care system as a whole. For example, an Okolona participant said the “health insurance company [incorrectly bills patients] just to make a buck. Because they really don’t care about your health. They are for profit.” A Fairdale participant added, “I would say [I trust] nobody. Because I feel like all of them are for profit. The doctors, the hospitals, the insurance companies.” Conversely, some described positive interactions with the health care system, specifically mentioning their primary care providers or the Veterans Health Administration.

Overall, navigating the health care system was challenging for most consumers. For those with significant medical issues, the stress and frustration of dealing with the system was an additional burden:

There are times when you’re just tired of it, you know? You’re tired of doctors and having to advocate for yourself. I know what it’s going to be like for me trying to get the answers that I need. And at this point, it just isn’t worth the hassle. —Individual interview participant

Health Insurance Information Delivery, Resources, and Support

Health insurance information was needed to select and enroll in appropriate plans, to understand and use a plan once enrolled, and to resolve problems related to health-care access and billing. Participants discussed their preferences for receiving this information. They preferred a combination of information delivery methods, tailored to their coverage, health care needs, level of understanding, and specific tasks (e.g., getting a bill resolved or selecting a new health plan). Participants perceived that print, online, phone, and in-person support each had positive and negative attributes. A common thread was that insurance information must be made easier to understand, whatever the delivery method.

Participants valued print materials as a tangible resource. They were considered especially useful in resolving disputes. However, lengthy manuals were unhelpful (“They make a great fire” —Fairdale participant). Unsolicited mailings were generally ignored. The most useful type of print information was a simplified comparison chart of different plans, although they noted this resource requires high HIL (“That helps, but you have to know how to read it, or have someone to read it for you” —Okolona participant).

Many participants were able to use their phone, tablet, or computer to connect to the internet and search for information, such as using personalized health insurance portals to find information or initiate an online chat with a representative. Simultaneously, they noted that others with limited computer literacy or access, particularly older adults, were unable to do so (“But here I am 64 and my aunt who is 85 is like “iPad? What? Cell phone? What? Give me that telephone!” —Okolona participant).

Participants described phone communication as important. In particular, they contacted their insurance company by phone to find information or resolve problems. Nonetheless, they commonly described frustration with automated systems and the length of time it took (“You can sit on that phone for a representative, you believe me, for two hours, then finally you get angry and hang up.” —Fairdale participant). Although many considered phone-based information reliable, some others were concerned about accuracy (“You want something in writing, that’s tangible. Somebody promised you something over the phone. Well, that’s not real” —Valley Station participant).

In-person communication was described in positive terms because, “you can ask the right questions... It’s more personable too, it’s more human” (Fairdale participant). Participants used in-person assistance for selecting and/or enrolling in plans and were able to get specific answers. They emphasized the importance of the messenger; not all sources of in-person assistance (e.g., family, friends, enrollment assisters, human resources staff, and insurance company representatives) were considered accurate and trustworthy. Insurance company representatives were perceived to have important information, but some participants expressed mistrust. Similarly, human resources and union representatives were often considered important resources for those enrolled in ESI or employer-sponsored retirement health plans, but some perceived a conflict of interest. Many turned to their healthcare providers for guidance about coverage and cost but acknowledged that they can provide inaccurate information. Overall, participants agreed that access to someone who could provide neutral and clear information tailored to an individual’s needs would be the most valuable.

DISCUSSION

Our research explored the HIL of South Louisville residents, how HIL affected their health behavior, and how individuals encounter the distinct but interrelated aspects of health care system navigation, enrolling in health insurance, and accessing care. Ideally, interactions with these processes should be simple and intuitive, leading to enrollment in appropriate coverage and access to high-quality, affordable health care.

However, as research shows, people with insurance may still have problems in accessing care and paying for services (Carrillo et al., 2011; DeVoe et al., 2007; Long et al., 2014; Morgan et al., 2008; Tipirneni et al., 2018). The well-cited model by DeVoe et al. considers three hierarchical struggles to obtaining healthcare—insurance coverage, access to services, and costs (DeVoe et al., 2007). Building on this, the Health Care Access Barriers model describes financial, structural, and cognitive barriers to healthcare (Carrillo et al., 2011). Both models indicate that the risk of delayed or foregone care among the insured population is modulated by structural or financial barriers within the health care system, but neither considers the importance of HIL (Carrillo et al., 2011; DeVoe et al., 2007). Conversely, other studies describe the importance of low HIL as a factor contributing to delayed or foregone care but overlook persistent structural or financial barriers (Long et al., 2014; Morgan et al., 2008; Tipirneni et al., 2018).

This qualitative study further contextualizes HIL as an additional layer within the previous hierarchical models. While HIL is an important factor for appropriate insurance enrollment and use, this study found that the risk of delayed or foregone care remains even among insured consumers with adequate HIL. Our findings (**Figure 1**) emphasize that obtaining health care is strongly influenced both by the individual context (HIL knowledge, experience, and life circumstances), and structural context (complex, bureaucratic, and costly health-care system). For example, despite adequate HIL, participants expressed frustration at the time and effort spent determining the best plan, obtaining covered health services, and settling claims (often unsuccessfully). Additionally, for many insured participants, cost considerations influenced decisions to accept certain tests or treatments. This oftentimes resulted in delayed or foregone care.

Moreover, health insurance in the United States is tied to important life transitions. Becoming unemployed, changing employers, or retiring from the workforce due to age or disability are all major events that can force changes in insurance. Our results emphasized the importance of these periods of transition as key points during which additional HIL support is needed.

This study found that HIL gained from personal experience or that of family/friends was the most useful. Efforts to build HIL should focus on practical and experiential learning to prepare people for all aspects of insurance enrollment and coverage use. Information should be delivered in multiple formats (i.e., print, online, in-person), tailored to different contexts and populations, and presented in a clear and simplified manner. Also, in-person assistance must be from a trusted person who can provide relevant and accurate information.

Future work includes developing and piloting an HIL intervention that uses these findings and is tailored to the consumer's life transition and socioeconomic contexts. Evaluation of such an intervention should include not only an assessment of consumers HIL levels, but also their levels of stress and anxiety surrounding the experiences of enrollment and accessing care.

Structural contexts must also be considered when developing HIL interventions. State and federal initiatives should address systemic barriers to health care access and cost. Examples of approaches include legislation to protect consumers from surprise billing (Bluth, 2018) and the establishment of healthcare advocate offices as independent or governmental agencies to assist consumers and propose policy solutions (Hunt, 2018).

STUDY LIMITATIONS

This study has some limitations. Our sample was older and more female than the South Louisville population. This is consistent with the literature; older women tend to take on the burden of health care decision-making for families (Matoff-Stepp et al., 2014). We did not use standardized testing to assess participants' HIL, which may limit the comparison of our sample with quantitative studies. Instead, this qualitative study gathered contextual descriptions of participants' perceptions of their HIL, including their misconceptions and real-life experiences with health insurance. As with other qualitative research the intended aim of this data was not generalizability, but rather transferability, which refers to the extent of applicability of the study findings in comparable contexts (Houghton et al., 2013; Lincoln & Guba, 1985). The resulting model developed from the rich qualitative data (**Figure 1**) provides a better understanding of the relationship between consumers' HIL and their health care experiences and applies to contexts outside of the working-class community of South Louisville.

As debates over health care and health insurance continue to feature on the national stage, the pace of change is unlikely to slow. To protect people from destabilizing health care costs and reduce the risk of delayed or foregone care, this study's findings provide context for developing HIL interventions and addressing systemic barriers to improve healthcare access.

REFERENCES

- Ali, N. M., Combs, R. M., Muvuka, B., & Ayangeakaa, S. D. (2018). Addressing health insurance literacy gaps in an urban African American population: A qualitative study. *Journal of Community Health, 43*(6), 1208–1216. <https://doi.org/10.1007/s10900-018-0541-x> PMID:29926271
- Barnes, A. J., Hanoch, Y., & Rice, T. (2015). Determinants of coverage decisions in health insurance marketplaces: Consumers' decision-making abilities and the amount of information in their choice

- environment. *Health Services Research*, 50(1), 58–80. <https://doi.org/10.1111/1475-6773.12181> PMID:24779769
- Benitez, J. A., Adams, E. K., & Seiber, E. E. (2018). Did health care reform help Kentucky address disparities in coverage and access to care among the Poor? *Health Services Research*, 53(3), 1387–1406. <https://doi.org/10.1111/1475-6773.12699> PMID:28439903
- Bluth, R. (2018, September 19). *Senators unveil legislation to protect patients against surprise medical bills*. Kaiser Health News. <https://khn.org/news/senators-unveil-legislation-to-protect-patients-against-surprise-medical-bills/>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Buchino, S., Wendel, M., & Combs, R. (2016, December). *Policy brief: Medicaid expansion in Kentucky*. Commonwealth Institute of Kentucky. <https://louisville.edu/sphis/departments/cik/docs-and-pdfs-1/medicaid-expansion-policy-brief>
- Carman, K. G., Eibner, C., & Paddock, S. M. (2015). Trends in health insurance enrollment, 2013–15. *Health Affairs (Project Hope)*, 34(6), 1044–1048. <https://doi.org/10.1377/hlthaff.2015.0266> PMID:25947173
- Carrillo, J. E., Carrillo, V. A., Perez, H. R., Salas-Lopez, D., Natale-Pereira, A., & Byron, A. T. (2011). Defining and targeting health care access barriers. *Journal of Health Care for the Poor and Underserved*, 22(2), 562–575. <https://doi.org/10.1353/hpu.2011.0037> PMID:21551934
- Creel, L., & Buchino, S. (2016, October). *ACA implementation in metro Louisville: Outreach, enrollment, and the remaining uninsured*. Commonwealth Institute of Kentucky. <https://louisville.edu/sphis/departments/cik/docs-and-pdfs-1/aca-research-brief-10-10-2016>
- Devoe, J. E., Baez, A., Angier, H., Krois, L., Edlund, C., & Carney, P. A. (2007). Insurance + access not equal to health care: Typology of barriers to health care access for low-income families. *Annals of Family Medicine*, 5(6), 511–518. <https://doi.org/10.1370/afm.748> PMID:18025488
- Edward, J., Wiggins, A., Young, M. H., & Rayens, M. K. (2019). Significant disparities exist in consumer health insurance literacy: Implications for health care reform. *HLRP: Health Literacy Research and Practice*, 3(4), e250–e258. <https://doi.org/10.3928/24748307-20190923-01> PMID:31768496
- Hoerl, M., Wuppermann, A., Barcellos, S. H., Bauhoff, S., Winter, J. K., & Carman, K. G. (2017). Knowledge as a predictor of insurance coverage under the Affordable Care Act. *Medical Care*, 55(4), 428–435. <https://doi.org/10.1097/MLR.0000000000000671> PMID:27820594
- Houghton, C., Casey, D., Shaw, D., & Murphy, K. (2013). Rigour in qualitative case-study research. *Nurse Researcher*, 20(4), 12–17. <https://doi.org/10.7748/nr2013.03.20.4.12.e326> PMID:23520707
- Hunt, A. (2018, April). *The office of the healthcare advocate: Giving consumers a seat at the table*. Healthcare Value Hub. <https://www.healthcarevaluehub.org/advocate-resources/publications/office-healthcare-advocate-giving-consumers-seat-table>
- Kelly Pryor, B., Hollenbach, R., Barber, A., & Gonzales, T. (2017). *2017 Health Equity Report: Uncovering the root causes of health*. Center for Health Equity, Louisville Metro Department of Public Health and Wellness. <https://louisvilleky.gov/government/center-health-equity/health-equity-report>
- Kim, J., Braun, B., & Williams, A. D. (2013). Understanding health insurance literacy: A literature review. *Family and Consumer Sciences Research Journal*, 42(1), 3–13. <https://doi.org/10.1111/fcsr.12034>
- Krueger, R. A. (2014). *Focus groups: A practical guide for applied research*. SAGE Publications.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. SAGE Publications. [https://doi.org/https://doi.org/10.1016/0147-1767\(85\)90062-8](https://doi.org/https://doi.org/10.1016/0147-1767(85)90062-8)
- Loewenstein, G., Friedman, J. Y., McGill, B., Ahmad, S., Linck, S., Sinkula, S., Beshears, J., Choi, J. J., Kolstad, J., Laibson, D., Madrian, B. C., List, J. A., & Volpp, K. G. (2013). Consumers' misunderstanding of health insurance. *Journal of Health Economics*, 32(5), 850–862. <https://doi.org/10.1016/j.jhealeco.2013.04.004> PMID:23872676
- Long, S. K., Shartzter, A., & Politi, M. C. (2014, October 27). *Low levels of self-reported literacy and numeracy create barriers to obtaining and using health insurance coverage*. Urban Institute Health Policy Center. <http://hrms.urban.org/briefs/Low-Levels-of-Self-Reported-Literacy-and-Numeracy.html>
- Matoff-Stepp, S., Applebaum, B., Pooler, J., & Kavanagh, E. (2014). Women as health care decision-makers: Implications for health care coverage in the United States. *Journal of Health Care for the Poor and Underserved*, 25(4), 1507–1513. <https://doi.org/10.1353/hpu.2014.0154> PMID:25418222
- Mayo, R., Griffin, S., Pribonic, A., & Rollins, M. (2016). The reality of the affordable care act implementation among the chronically uninsured: A qualitative study. *Diversity and Equality in Health and Care*. <https://www.primescholars.com/articles/the-reality-of-the-affordable-care-act-implementation-among-the-chronically-uninsured-a-qualitative-study-94867.html>
- Morgan, D. L. (2018). *Basic and advanced focus groups*. SAGE Publications. <https://doi.org/10.4135/9781071814307>
- Morgan, R. O., Teal, C. R., Hasche, J. C., Petersen, L. A., Byrne, M. M., Paterniti, D. A., & Virnig, B. A. (2008). Does poorer familiarity with Medicare translate into worse access to health care? *Journal of the American Geriatrics Society*, 56(11), 2053–2060. <https://doi.org/10.1111/j.1532-5415.2008.01993.x> PMID:19016939
- Muvuka, B., Combs, R. M., Ayangeakaa, S. D., Ali, N. M., Wendel, M. L., & Jackson, T. (2020). Health literacy in African-American communities: Barriers and strategies. *HLRP: Health Literacy Research and Practice*, 4(3), e138–e143. <https://doi.org/10.3928/24748307-20200617-01> PMID:32674161
- Norton, M., Hamel, L., & Brodie, M. (2014, November 11). *Assessing Americans' familiarity with health insurance terms and concepts*. <https://www.kff.org/health-reform/poll-finding/assessing-americans-familiarity-with-health-insurance-terms-and-concepts/>
- Paez, K. A., Mallery, C. J., Noel, H., Pugliese, C., McSorley, V. E., Lucado, J. L., & Ganachari, D. (2014). Development of the health insurance literacy measure (HILM): Conceptualizing and measuring consumer ability to choose and use private health insurance. *Journal of Health Communication*, 19 (Suppl. 2), 225–239. <https://doi.org/10.1080/10810730.2014.936568>
- Patient Protection and Affordable Care Act of 2010, Pub. L. No. 111-148, 124 Stat. 119. (2010). <https://www.congress.gov/111/plaws/publ148/PLAW-111publ148.pdf>
- Quincy, L. (2012a, February). *Measuring health insurance literacy: A call to action*. Consumers Union. https://advocacy.consumerreports.org/wp-content/uploads/2013/03/Health_Insurance_Literacy_Round-table_rpt.pdf
- Quincy, L. (2012b, January). *What's behind the door: Consumers' difficulties selecting health plans*. Consumers Union. https://advocacy.consumerreports.org/wp-content/uploads/2013/03/Consumer_Difficulties_Selecting_Health_Plans_Jan2012.pdf
- Tipirneni, R., Politi, M. C., Kullgren, J. T., Kieffer, E. C., Goold, S. D., & Scherer, A. M. (2018). Association between health insurance literacy and avoidance of health care services owing to cost. *JAMA Network Open*, 1(7), e184796–e184796. <https://doi.org/10.1001/jamanetworkopen.2018.4796> PMID:30646372
- U.S. Census Bureau. (2016). *American Community Survey. Data profiles*. <https://www.census.gov/acs/www/data/data-tables-and-tools/data-profiles/2016/>
- Witters, D. (2017, February 8). *Kentucky, Arkansas post largest drops in uninsured rates*. Gallup. <http://www.gallup.com/poll/203501/kentucky-arkansas-post-largest-drops-uninsured-rates.aspx>