Young Adult's Perspectives on Being Uninsured and Implications for Health Reform

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Abstract
Young adults between the ages of 18-34 are most likely to lack health insurance in the United States. The Affordable Care Act (ACA), a federal statute signed into law in 2010, contains provisions specific to increasing access to health insurance for young adults including the provision that persons under 26 can stay on their parents’ insurance. While the reasons for uninsurance among young adults have been documented, how they operate and are perceived on an individual level have not been explored in great detail. Further, it is poorly understood how the ACA policies and the state health insurance exchanges can serve young adults. Thus, we interviewed uninsured young adults aged 18-35 in northeastern Minnesota and northwestern Wisconsin and used inductive thematic analysis to explore these issues. Findings suggest that young adults don’t feel at risk for health problems and therefore have low levels of health insurance literacy and place little value on health insurance. Multiple barriers to health insurance coverage, including the provision about staying on a parent’s policy, persist despite the ACA. Our findings also suggest valuable lessons for state health insurance exchanges on how to better serve this population.

Keywords
Health Care Access, Health Insurance, Health Policy, Young Adults, Interviews, Inductive Thematic Analysis

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Young Adult’s Perspectives on Being Uninsured and Implications for Health Reform

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Young adults between the ages of 18-34 are most likely to lack health insurance in the United States. The Affordable Care Act (ACA), a federal statute signed into law in 2010, contains provisions specific to increasing access to health insurance for young adults including the provision that persons under 26 can stay on their parents’ insurance. While the reasons for uninsurance among young adults have been documented, how they operate and are perceived on an individual level have not been explored in great detail. Further, it is poorly understood how the ACA policies and the state health insurance exchanges can serve young adults. Thus, we interviewed uninsured young adults aged 18-35 in northeastern Minnesota and northwestern Wisconsin and used inductive thematic analysis to explore these issues. Findings suggest that young adults don’t feel at risk for health problems and therefore have low levels of health insurance literacy and place little value on health insurance. Multiple barriers to health insurance coverage, including the provision about staying on a parent’s policy, persist despite the ACA. Our findings also suggest valuable lessons for state health insurance exchanges on how to better serve this population. Keywords: Health Care Access; Health Insurance; Health Policy; Young Adults; Interviews; Inductive Thematic Analysis

Currently, over 48 million people in the United States lack health insurance (DeNavas-Walt, Proctor, & Smith, 2012). Further, recent research suggests that nearly half of the adult population is either uninsured, experienced uninsurance at least once in the past year, or were not protected from extraordinary out-of-pocket medical costs associated with high deductible individual plans in 2012 (Collins, Robertson, Garber, & Doty, 2013). Close to 25% of those 18-24 and 28% of those 25-34 are uninsured, whereas only 14.7% of the overall population are uninsured (Cohen & Martinez, 2013).

Review of the Literature

It is well documented that a lower income is associated with not having health insurance (Schwartz & Schwartz, 2008) and it is costly to purchase health insurance in the open market (meaning the market outside of employer-sponsored coverage). However, even employed young adults face significant barriers to having health insurance. Young adults are more likely to be un- or under-employed and thus less likely to have employer-sponsored insurance or to afford the premiums associated with health insurance. Research suggests that close to one-quarter of young adults offered employer-sponsored insurance turn it down due to the expense. Young adults also tend to have lower wages even in full time jobs and face hurdles imposed by employers (e.g. having to work for a certain period of time before becoming eligible; Holahan & Keeney, 2008; Collins et al., 2013). A lack of a college education can compounding the problem. Uninsured young adults are more than twice as likely as privately insured young adults to have no education beyond high school. Furthermore,
people with less education are less likely to seek employment with large firms, which are more likely to provide health insurance as a benefit (Schwartz & Schwartz, 2008).

Young adults are less likely to enroll in employer-sponsored insurance because of good health and the attitude that health insurance is not important. Compared to adults 27 years and older, adults 26 years and younger are less likely to believe that health insurance is necessary even after controlling for health status (Holahan & Keeney, 2008). These data strengthen the stereotype pointed out by Collins and colleagues that young adults consider themselves to be “invincible” (2012). Data from focus groups conducted by the Minnesota Department of Health (Krueger & Associates, 2002) support the sentiment that health insurance lacks value. The young adults participating in the focus groups felt health insurance was not worth what it costs and that they would pay more for insurance than they currently spend on health care.

Additionally, it is difficult for young adults to access government-sponsored health programs, such as Medicaid. A majority of the young adults between the ages of 19-34 do not qualify for government health programs due to strict limitations on eligibility (Schwartz & Schwartz, 2008). According to Holahan and Kenny (2008), only 13% of uninsured young adults could be enrolled in Medicaid or other public coverage, which leaves them at the highest risk of not receiving needed medical attention (2008). In addition to eligibility, other barriers to using government-sponsored insurance include a lack of knowledge about eligibility, how, and where to apply; concerns about welfare eligibility; and barriers related to income documentation and the application process (Stuber & Bradley, 2005). Clearly government safety-net programs have a long way to go in addressing access issues facing the young adult population.

Without insurance, young adults choose to skip recommended treatments, tests and follow up visits; avoid seeking necessary medical attention; forgo purchasing prescribed medications, or are paying off medical debt (Callahan & Cooper, 2005; Collins et al., 2012). Young adults are also more likely to lack a usual source of care, which can have long-term consequences for their health. It appears the lack of health insurance, independent of income, is most strongly associated with not seeking care (Ross, Bradley, & Busch, 2006). These data suggest that increasing health insurance coverage could improve health status and point out the potential for success of Affordable Care Act (ACA) policies that seek to increase coverage.

The ACA is a lengthy and complex piece of federal legislation designed to increase access to health insurance coverage in the United States. It is expected to expand health insurance to over 30 million persons, including many young adults. One way the ACA sets out to accomplish this is through the individual mandate and its counterpart, state health insurance exchanges – online marketplaces where uninsured individuals can purchase a health insurance plan. Another way the ACA sets out to tackle uninsurance is by giving young adults the opportunity to remain on a parent’s health insurance plan until the age of 26, a provision which has decreased the numbers of uninsured young adults by an estimated three million persons (Sommers, Buchmueller, Decker, Carey, & Kronick, 2013). Although these data are promising, there will still be close to 20 million persons without insurance and an untold number that will continue to face financial and other barriers. The provision that young people can stay on their parents’ insurance until age 26 assumes that parents have insurance and have the means to keep a child on their policy, while in fact, this additional cost has been prohibitive for some parents (Collins et al., 2013). That the traditional safety-net programs have not focused their attentions on young adults also suggests that government programs should build trust with the young adult population before enrolling them in programs. Last, it is not well understood how the barriers to having health insurance interact
with each other, are perceived by individuals, or how proposed policy solutions may help the problem in this population.

As such, the purpose of this study was to investigate the reasons behind not having health insurance qualitatively and in light of recent policy changes. First, we could find just one qualitative study on the topic (Krueger & Associates, 2002). The lack of qualitative data is concerning because it does not provide in-depth information on how barriers to health insurance affect and act upon the young adult population, only that they exist. Second, our purpose was to gather information on how the ACA and the state health insurance exchanges can enroll young adults in health insurance and better serve this population. The Obama administration has made it clear that young, healthy adults need to use state health insurance exchanges to enroll in health insurance plans in order to spread health insurance costs out across the population of insured persons and offset the high costs of insuring persons who are critically ill, and who presumably use more health care services. Another limitation of the quantitative body of literature is that we do not know the effects of this act, particularly as they act across socio-economic status (Sommers et al., 2013). Our participants, all uninsured, allowed us to explore issue of uninsurance among those of lower socio-economic status and offer policy solutions based on the perspectives of the population.

Methods

Origins of the Research

The lead author (Dr. Dauner) is an Assistant Professor of Health Care Management who has experience conducting qualitative research for the purpose of program and policy evaluation. She was approached by a community organization whose mission is to increase access to care in the “Twin Ports” communities (an area encompassing Duluth, Minnesota; Superior, Wisconsin; and the surrounding area in the upper Midwest United States) to study the issue. They were interested in preparing for an increase in the numbers of insured young persons as a result of the ACA and wanted their efforts to be well-received by young adults in the community. They also had anecdotal information that there were still numerous barriers to care for those persons under the age of 26, despite the efforts of the ACA to increase access to this age group. Thus, they wanted to understand the problem better and solicit information that would inform their outreach prior to the implementation of the state health insurance exchange as they planned on becoming an organization certified to provide navigation services to users of the exchanges (for more information on what navigators do see Norman, 2013). Dr. Dauner then engaged her health services research methods class in conducting the research. Her students are all undergraduate health care management majors who have taken coursework on the U.S. health care system and in research methods. As the goal of the research was to identify and examine the problem of uninsurance in a transparent and credible way and make recommendations for programs and policies, Dr. Dauner decided to use an inductive thematic approach to analyze the issue. Likewise, the quantitative body of literature suggested predetermined themes that would be useful for the development of our discussion guide and initial analysis (Guest, MacQueen, & Namey, 2012). The second author was a student in the class who, upon graduation, volunteered to continue the data analysis with Dr. Dauner.
Study Location and Relevance

This study was conducted in the “Twin Ports” communities of Duluth, Minnesota and Superior, Wisconsin, located at the Western tip of Lake Superior, in the upper Midwest United States. The total population of the metropolitan area is just under 300,000; however, the health care organizations of the two communities serve a large geographical area that is predominantly rural and encompasses northern Minnesota, Wisconsin, and parts of the Upper Peninsula of Michigan. Locally, 15% of men and 21% of women ages 18-34 are uninsured, which is a bit lower than national figures but higher than the 9% of the overall local population reporting being uninsured. Like national data demonstrate, poverty and lower educational levels are associated with uninsurance (Finch et al., 2010).

This study is relevant for many reasons. When compared to the nation, persons in Minnesota and Wisconsin, the Northeast, and Colorado experience a lower risk of and shorter duration of uninsurance. At the same time, these areas have higher turnover in public insurance programs and half of newly uninsured persons are between the ages of 18-34 (Graves & Swartz, 2013). These data suggest that the nature of uninsurance varies across states and therefore different states health insurance exchanges (or even multi-state regions) ought to use different enrollment strategies based on what they know about uninsurance in their area. Our research begins this effort for the Twin Ports area, and, despite a local focus, our research may be applicable for states and regions with similar uninsurance patterns.

In addition, the most recent Kaiser Family Foundation (2013b) poll found that over half of the respondents did not understand how the ACA would impact them or their families. Awareness of the various provisions of the law has remained unchanged since its enactment in 2010 and most people reported not having a trusted source for information on the law. Awareness that the exchanges opened on October 1, 2013 was low overall and even lower (just 12%) among the insured. Thus, it is critical to assess how information about health insurance is obtained by the young adult population so that the state can inform outreach and marketing efforts. Such efforts seem to be needed nationally, given the widespread confusion over the law and how consumers can make use of its benefits.

Study Procedures

First, a semi-structured interview guide was developed using an iterative process among the students (who eventually conducted the interviews), health services researchers, and two community organizations that work with the uninsured community prior to its use. A literature review also informed the interview guide. Before data collection all student interviewers went through Human Subjects Research training from the University of Miami’s online CITI Program. Interviewers also received two, one-hour classroom-based trainings on conducting interviews. This training included role-play exercises and training on the use of digital audio recording equipment. Interview participants were recruited through word-of-mouth and flyers placed in areas where uninsured persons would see them (e.g. local food shelves, bus transfer stations, laundromats, a free clinic, and an emergency food shelf and shelter for low-income or homeless adults) and subsequently our interviews took place in many of these locations. Two-person interview teams carried out the interviews. Teams consisted of an interviewer and a note-taker. Each team consisted of one male and one female who were in the same age range of the participants, to provide a comfortable and safe environment for the participants. We conducted interviews with 35 uninsured young adults between the ages of 18 and 35 in late 2012, just before efforts to market the Minnesota Health Insurance Exchange began in earnest. Interview teams did not interview any persons that they recruited via word-of-mouth, instead those persons were interviewed by another team. At the
beginning of each interview, the interviewer reviewed the study purpose and interview protocol, received permission to record the interview via a digital audio recorder, and emphasized the confidential nature of the interviews. Participants also filled out a brief questionnaire prior to the interview. The questionnaire contained questions on demographics, health status, financial priorities, and reasons for being uninsured. Interviews lasted approximately 20 minutes. Participants received a $10 gift card to a local grocery store chain for their time. After the interviews, all audio recordings were transcribed verbatim. The note-taker’s handwritten notes were used to supplement the audio recording. Upon completion of the interview, the interview team compared notes and briefly discussed them in order to ensure their accuracy. All interview guides and procedures were approved by the University of Minnesota’s Institutional Review Board.

Data Analysis

Data were analyzed using a process of identifying, coding, and clustering patterns and themes, and then selecting, ordering, and categorizing them (Patton, 2001). First, a small team of students developed an initial codebook and coded 10 transcripts. After, class discussion was used to refine codes. Then, two researchers (the two authors) independently coded each transcript by building upon the initial set of codes and built consensus on final themes and meanings.

Results

Characteristics of Interview Participants

Table 1 presents the full demographic, health status and current life priorities of the 35 participants. Of the participants, the majority (57%) were female. The predominant race/ethnicity was Caucasian (60%); however, racial and ethnic minorities were overrepresented compared to the Twin Ports population and represented 40% of participants. The average age was just under 24 years. Approximately one-third were currently enrolled in college; many of these participants were also working at least part-time in addition to being in school. Participants cited rent as their number one priority, with education a close second. Health insurance ranked third in terms of most frequently cited life priority, but was far behind rent and education. Most felt their health was at least as good as others their age and on average participants had been without insurance for three years.

<p>| Table 1: Characteristics of the Interview Participants |
|-----------------------------------------------|-------------|--------|
| Characteristic                                | Number      | Percent|
| Number of Respondents (N)                     | 35          |        |
| Gender Distribution                           |             |        |
| Female                                       | 20          | 57%    |
| Male                                         | 15          | 43%    |
| Race/Ethnicity Distribution                   |             |        |
| Caucasian/White                              | 21          | 60%    |
| African American                             | 8           | 22.9%  |
| Asian/Pacific Islander                       | 4           | 11.4%  |</p>
<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Native American</td>
<td>1</td>
<td>2.9%</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2.9%</td>
</tr>
<tr>
<td><strong>Age Distribution</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>18-35</td>
<td></td>
</tr>
<tr>
<td>Average Age</td>
<td>23.8</td>
<td></td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Part-Time</td>
<td>15</td>
<td>42.9%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>8</td>
<td>22.9%</td>
</tr>
<tr>
<td>Full-Time</td>
<td>7</td>
<td>20%</td>
</tr>
<tr>
<td>Student</td>
<td>12</td>
<td>34.3%</td>
</tr>
<tr>
<td><strong>Highest Level of Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some College</td>
<td>20</td>
<td>57.1%</td>
</tr>
<tr>
<td>High School Diploma</td>
<td>10</td>
<td>28.6%</td>
</tr>
<tr>
<td>Bachelor Degree</td>
<td>2</td>
<td>5.7%</td>
</tr>
<tr>
<td>Vocational/Technical School</td>
<td>1</td>
<td>2.9%</td>
</tr>
<tr>
<td>Less than High School</td>
<td>1</td>
<td>2.9%</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2.9%</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
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<td></td>
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<tr>
<td>Single</td>
<td>33</td>
<td>94.3%</td>
</tr>
<tr>
<td>Living with another</td>
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<td>5.7%</td>
</tr>
<tr>
<td><strong>Perceived Health Status Compared To Others</strong></td>
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<td></td>
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<tr>
<td>Excellent</td>
<td>8</td>
<td>22.9%</td>
</tr>
<tr>
<td>Good</td>
<td>22</td>
<td>62.9%</td>
</tr>
<tr>
<td>Fair</td>
<td>5</td>
<td>14.3%</td>
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<tr>
<td>Poor</td>
<td>0</td>
<td>0%</td>
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<tr>
<td><strong>Has Chronic or Recurrent illness</strong></td>
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<td></td>
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<tr>
<td>Yes</td>
<td>6</td>
<td>17.1%</td>
</tr>
<tr>
<td>No</td>
<td>29</td>
<td>82.9%</td>
</tr>
<tr>
<td><strong>Has Sustained Significant Injury</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>8</td>
<td>22.9%</td>
</tr>
<tr>
<td>No</td>
<td>27</td>
<td>77.1%</td>
</tr>
<tr>
<td><strong>Has Been To The Emergency Room</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>12</td>
<td>34.3%</td>
</tr>
<tr>
<td>No</td>
<td>23</td>
<td>65.7%</td>
</tr>
<tr>
<td>Life Factor Ratings</td>
<td>Freq. of being most important</td>
<td></td>
</tr>
<tr>
<td>--------------------------</td>
<td>-------------------------------</td>
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</tr>
<tr>
<td>Rent</td>
<td>19</td>
<td></td>
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<tr>
<td>Education</td>
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<td></td>
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<tr>
<td>Health Insurance</td>
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<td></td>
</tr>
<tr>
<td>Groceries</td>
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<td></td>
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<tr>
<td>Other Activities</td>
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<td></td>
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<tr>
<td>Clothes</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Car Expenses</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

**Key Themes of the Interviews**

Key themes of the interviews included:

1) Lack of feeling at risk for health problems and subsequently feeling that health insurance lacked value,
2) Lack of health insurance literacy,
3) Barriers to health insurance, including barriers related to the Affordable Care Act and
4) Lessons for the state health insurance exchanges.

**Not at risk and so health insurance lacks value**

Participants had a strong perception that they were not at risk for serious health issues. Participants pointed to a lack of immediate need and perception of not being at risk and these feelings play a critical role in the observed lack of health insurance literacy and why young adults do not value health insurance. It is perceived that having health insurance but not using covered health care services is “money wasted.” As put by one interviewee, illustrating the relationship between cost and health:

Day to day it can sometimes kind of be seen as a waste of money from your daily paychecks, or monthly paychecks...like I said before I’m not really a sick person so – I don’t really see that as part of my budget.

Participants who grew up having health insurance through their parents seemed to place the lowest value on health insurance. Some felt that it was something their parents paid for, but that they never “used” due to their good health. Others took for granted the fact that they had health insurance growing up.

I guess I kind of just took it for granted when I was with my parents. Because, obviously when I got sick I would tell my mom or dad and I would go to the doctor and I would get taken care of.

At the same time, sentiments changed drastically when participants had children of their own. Those participants with children indicated the value of health insurance for their children. As one participant stated, “Well I have a son – and I would say [health insurance]
became more important.” Those without children felt it was important if they had family; however, it was mentioned only in the abstract for those participants. The lack of value placed on health insurance also related to a lack of health insurance literacy.

Lack of health insurance literacy

Participants expressed confusion on a number of issues related to the purpose of health insurance, how to obtain health insurance, and premiums and other types of cost sharing. The ACA and its provisions only added to this confusion. When it comes to obtaining health insurance, many felt that health insurance was something that is obtainable at the point of service (e.g. in the emergency department). As well, how and when to pay seemed too frequent and often arbitrary (as when one pays a monthly premium and then a copayment for services), and was poorly understood. Participants also expressed a general apathy towards becoming knowledgeable on the topic. The quotes below illustrate these sentiments.

I really don’t feel like I need it. I don’t take any prescriptions, I don’t go to the hospital and do doctor-appointments or check-ups or anything like that. I feel fine, and if an illness does come down, I’ll just go through the motions and let it pass.

Everybody needs insurance – I guess I could go to the government building or wherever they’re giving it out at I don’t know. I guess I don’t need it at the time so when I need it then I can just go figure out where I can get it from.

See I’m not quite sure how it works, see if they do a dollar a day or something, or is it like every time you go in or…?

The ACA adds to the complexity of our already complicated health care system and this only exacerbated the confusion expressed by participants. While general awareness of governmental health reform efforts (often expressed in terms of “Obamacare”) among all respondents was high, most did not understand the individual mandate or how it would affect them in 2014, when there would be financial penalties for not having qualifying (encompassing a specific set of benefits) health insurance. Participants interpreted Obamacare to be insurance that they could acquire for themselves and their family and did not understand that the term referred to a set of policies aimed at reforming many aspects of the health care system. One particular participant illustrates this theme.

That’s a plus... you know, some kids they don’t want to do all the paperwork and get their own insurance and they just want to stay in school and college and not deal with all that. So yeah, that’s a plus. Hmmm, so that’s what I should go for then, I should get on Obamacare.

The presence of past medical issues both required and enabled a higher level of health insurance literacy. Some participants seemed to have prior experience being underinsured and expressed concern when faced with the possibility of paying for a medical problem out-of-pocket or forgoing care. As one participant put it:
At first when I had [health insurance] – it didn’t mean much but then now that I don’t have it and I have asthma and I have to pay for my asthma stuff – and its like $220 – and then I realized how important it is.

In general, participants seemed much more familiar with emergency care. At times, participants criticized providers for not extending past their obligation to give necessary care, which reflects the use of more emergency care versus regular care. They suggested that “necessary” medical care might not cover all the bases in terms of a patient’s needs, and that more primary care services would be useful and are needed. This theme illustrates the scope of health insurance illiteracy; additionally showing how attitudes are shaped and perspectives are changed with changes in health status.

They [a health insurance plan the participant used to have] have certain coverage and certain things they do not cover, and they have it basically whenever you go to a doctor you ask them certain questions and well “your insurance doesn’t cover that.”

**Barriers to health insurance**

Participants described numerous barriers to health insurance. Cost barriers were talked about the most in all interviews. Participants expressed the price of obtaining and keeping health insurance as an unviable financial and personal option. Simply not being able to fit health insurance in their budget was commonly expressed; but most importantly respondents noted this in terms of lost employment, educational, and opportunity costs. Part-time employment was a large barrier to health insurance because many of their employers did not offer health insurance to part-time employees. Likewise, if employers did offer health insurance, it was apparent that respondents felt the benefits were not worth the extra financial strain. As one participant described it,

If you buy your own health insurance they’ll reimburse you up to $150 a month for it. So you’re still paying this huge sum out of pocket – I mean they’ll reimburse you for it, but you got to start somewhere, it’s like I don’t have even $150 to even start.

In addition, some participants felt that the health insurance offered by their employers was inadequate due to certain treatments and procedures not being covered or high cost sharing. Despite early provisions of the ACA that eliminate pre-existing condition clauses and lifetime limits, participants still felt that high cost-sharing arrangements (e.g. the need to meet high deductibles and coinsurance) prohibited care and incurred debt. This suggests underinsurance as another issue among the participants. Many expressed that their lack of insurance was purely temporary, that finishing their current goals and aspirations would later enable them to have more fulfilling employment with employer-sponsored health insurance. Twelve participants were in school and many of these were working full or part time in addition to being in school. Many of them made clear that their priority was to finish school. Further, several participants did not just work one part-time job, but many. “I never really sought out private [health insurance] companies right now. I might as well just wait to be done with school and then I can get it through my work.”

Cost barriers were also expressed as a tradeoff or opportunity cost. In other words, fitting health insurance into one’s budget extended past financial concerns alone, and was weighed against the costs of crucial life decisions – such as staying in school, living
situations and employment status. For some, obtaining health insurance would equate to moving back in with their parents because of an inability to pay for rent, and this was unpalatable. For others, the tradeoff of obtaining health insurance meant changes in employment and student status. Some students were enrolled in local community colleges that did not require students to carry health insurance. A respondent who was a student explains these tradeoffs:

It’s not offered through any of my jobs and being in school and having rent I can’t afford to have it on my own… in order to get health insurance I would have to make more money. Or, I would have to become a full time employee and then I wouldn’t be able to go to school.

Some participants had tried to enroll in state-sponsored health insurance programs but noted that they were denied on the basis of making too much money. Paperwork also posed a barrier to seeking such health insurance. The submittal and resubmittal of additional information and the time period (4-6 weeks) for approval or denial proved to be mentally exhausting enough to stop trying to get health insurance. As one participant put it:

I just wish it was easier to get insurance. When I tried to get insurance every time I’d send something in they would send something back saying that they needed more stuff; and it was like never ending. No matter what they did they always needed something else from me.

Financial and opportunity cost barriers also compound the feeling that health insurance is not a priority. Our quantitative findings provide further support for this finding. Participants ranked health insurance well behind rent and education as a priority. These barriers also offer insight into where young adult’s health insurance desires rest: cheaper, easier access, and far less rigorous administrative paperwork.

Participants under the age of 26 were also asked about staying on their parent’s insurance until the age of 26. However, having the new ability to stay on their parent’s insurance through 26 did not affect them. Frequently, parents did not have health insurance due to employment status, job switching, and contract work and these were cited as reasons why this ACA benefit was not being utilized. When a participant’s parent did have health insurance, the participant often was unable to take advantage of it. This was due to a variety of personal (i.e. a parent not willing to extend the benefit, or no relationship with parent), insurance plan (i.e. coverage not extending to family) and financial constraints (i.e. the cost of an additional individual on the plan proved to be too burdensome). The quotes below illustrate the barriers faced by participants and their parents.

…so with my parents both [they] have gone through different jobs and their insurances are switching all the time – so I guess it’s just really tough to hold that.

And I actually can get insurance now under my Mom’s work but I have to pay for it and it’s like $140 a month which, I can’t afford that right now.

**Lessons for state health insurance exchanges**

A final theme in our research focuses on what key players and institutions can do moving forward to meet these demands through state health insurance exchanges.
Participants were asked how they obtain information on health insurance. Here the Internet was the preferred venue for seeking out information on health insurance. Respondents desired autonomy in researching insurance options, but at the same time stressed the need for a strong level of organization. Such organization would ensure that the importance of health insurance is effectively and clearly communicated to consumers, which, in turn, could potentially decrease health insurance illiteracy and apathy.

Other preferred locations for receiving information on health insurance was at the point of service or in a healthcare setting such as an emergency department or urgent care center. Participants expressed it is in these settings where they have had some contact with health care; as a result it is fitting to make information regarding insurance, healthcare, and the individual mandate readily available for them in these settings. Furthermore, it is also recommended that individuals knowledgeable about this information also be present in these settings to provide one-on-one assistance. Other methods of achieving dissemination and outreach, most notably television, were almost unanimously seen as ineffective.

Some participants suggested the need for a lower-cost health insurance option for persons their age or attending college. Some felt having to pay for health insurance “penalized” them at a time when they were prioritizing education and this was unfair. Here is insight from one respondent:

I do wish there were more health insurance options for people in their mid to late 20s. A lot of us are starting out and with the economy these days it’s really difficult to find jobs right out of college… I have tried to find health insurance again; I felt tricked after reading the fine print… it is just very confusing for me and overwhelming at times.

The above quote illustrates that an affordable plan that is cheap and easy would be fitting and accepted – while full-coverage health insurance would not be financially feasible, nor make sense given good health status. Similarly, it will be necessary for the community and advocacy organizations providing outreach, navigation, and enrollment to appropriately link this population to available financial assistance (called advanced premium tax credits under the ACA) for health insurance in a way that is easy-to-understand, while minimizing the paperwork issues associated with Medicaid eligibility determination.

Discussion

The analysis of participants’ responses yielded interconnected and overlapping themes that helped to explain drivers behind high levels of uninsurance in the young adult population. Further, our findings add to the body of literature examining how health insurance literacy and health perception interact in young people and lead to uninsurance. Our findings are unique in that they take into consideration the current political landscape and provide policy solutions for state health insurance exchanges that are currently working to enroll this population in health insurance plans.

Limitations

At times participants provided binary “yes” or “no” responses to questions, even when questions were framed in an open-ended manner. It surfaced during our analysis that the questions that produced such responses were those focused on health insurance itself and that perhaps the lack of response is further indication of the low levels of health insurance literacy within the participant group. In addition, interviewer ability and ease may have been
an issue. While researchers were trained in the use of qualitative research techniques, there was variation among interview teams. Most interviewers were new to interviewing and were undergraduate students. Though we felt this was important in order to establish rapport with the interview participants, their inexperience potentially acted as a detriment to fully capturing the participants’ stories, which would have subsequently brought more texture to themes. However, our qualitative analysis indicated significant theme saturation and so we feel confident that this was only a minor issue.

Another limitation stems from the fact that the research was conducted in one community. At the same time, the Twin Ports is not unique in being a mid-sized city serving a large rural area. Research also suggests there is value in learning more local reasons for not having health insurance as the issue itself is not homogenous and that learning about the variation in health insurance dynamics can help tailor enrollment strategies for state health insurance exchanges (Graves & Swartz, 2013). Currently, however, it is unclear to what extent these themes would be found in other areas of the country and we feel similar studies in other areas of the country would be appropriate areas for future research. The literature on reasons behind uninsurance in young adults suggest that reasons for uninsurance are not dependent upon location, although the dynamics of insurance eligibility in private and public insurers may be. Our respondents mentioned similar themes regardless of state policy environment (e.g., Minnesota has a very well-developed state-run exchange, whereas Wisconsin will participate in the federally-run exchange), which indicates the issues themselves, are relevant across settings. Additionally, our policy recommendations hold true for both state-run and federal-run exchanges.

Implications for Policy

Our findings shed light on recent research suggesting that consumer awareness and trust of health insurance exchanges is quite low (Fronstin, 2012, Kaiser Family Foundation 2013b), and that emphasizes the need for state health insurance exchanges to use various outreach channels to reach uninsured consumers (Stawicki, 2012). Our findings suggest that placing health insurance information and conducting outreach where young uninsured adults usually receive care are recommended. A recent national poll demonstrated that people cite conversations and outreach as the way in which they received information regarding their state’s health insurance exchange (Kaiser Family Foundation, 2013a). Outreach must also dispel myths that Obamacare is a health plan. This is especially important considering that the same poll found that a startling majority of young adults believed that the ACA was either repealed by Congress or overturned by the Supreme Court (2013). In addition, our research suggests that online platforms as another good way to get information to young adults.

There is now federal funding for state consumer assistance programs, often termed “Navigator Programs”, and other ways in which to reach out to new health insurance consumers who will purchase health insurance coverage from the health insurance exchanges. The goals of such funding streams are to boost consumer health insurance awareness and provide community outreach so that persons without health insurance can purchase insurance through the exchange and take advantage of subsidies related to that purchase. Notably, these platforms should help consumers become more knowledgeable about health insurance, identify plans most suitable for them given their health status and risk tolerance, and should emphasize why health insurance is important at any age.

Additionally, consumer assistance and navigation should emphasize consumer empowerment when mentoring a consumer in the process of making decisions related to health insurance. Consumer empowerment has been touted by numerous other health insurance programs, including the Centers for Medicaid and Medicare Services, as crucial to
the prevention of health insurance illiteracy (Grob, Schlesinger, Davis, Cohen, & Lapps, 2013). Navigator programs and advocacy groups directing individuals through state exchanges will also need to effectively communicate different coverage options offered by many different plans, as existing research suggests that consumer confusion increases as the number of health insurance plan options increase. Minimizing confusion is vital since our research found that persons in this age range do not understand the notion of a premium, or how it is distinguished from a co-payment. Research also suggests that a simulator, in which consumer’s responses to hypothetical scenarios are used to steer them towards health insurance options, may be useful (Corlette, Downs, Monahan, & Yondorf, 2013). Ultimately the goal is for young consumers to match their perceived need for health insurance to a health insurance plan and our recommendations are intended to inform the organizations and individuals (e.g., navigators) who facilitate this.

Those we interviewed seemed to be looking for a health plan that is affordable and easy to use. They want a plan in which the financial obligations are worth the perceived benefits. Plans labeled “catastrophic” may fit that bill. However, education needs to be in place so that the consumer is aware of what such a plan entails. According the ACA, a catastrophic plan is only obtainable through the exchange to persons under 30, or who meet the qualifications of being exempt from the individual mandate. Catastrophic plans also exempt three primary care visits from the patient's deductible, cover care that is found to be preventative, and cover essential health benefits after the consumer has met their cost-sharing requirements. At the same time, cost sharing can be steep (individual $5950, or family $11,900) which may place additional and possibly unforeseen burdens on a young adult population. Other plans such as, “Bronze” plans (where insurance would cover 60% of costs and the enrollee 40%; which affords lower premiums) may be more palatable to young consumers. Still, the cost-sharing arrangements may prove to be financially steep. Again, the use of a simulator may help tease such issues out.

Our findings highlighted the issue of health insurance literacy. This concept is akin to health literacy, which is well documented in the existing literature on patient engagement. Additionally, just as third-party payers have become increasingly involved in the broader patient engagement movement, they are poised to offer potential solutions to the issue of health insurance illiteracy. Our research suggests that recent efforts by the U.S. health insurance industry to inform and engage health plan members in the decision-making process by providing cost estimates prior to receiving services, physician quality metrics, and cost-efficiency indicators may be especially effective for young adults (Yegian, Dardess, Shannon, & Carman, 2013). With respect to these efforts, state health insurance exchanges should take into consideration and adopt many of these practices in order to navigate consumers efficiently to the best health care plan for their needs. We feel this will ultimately lead to a more informed consumer decision, increase consumer trust in the exchange, improve health insurance literacy, and potentially act as a catalyst to better health care. In addition, our findings are useful for those countries that use private health insurance plans, with or without individual mandates, to ensure access to health care for their citizens.

The study shows that these are many areas of concern for the uninsured population under 35 years of age and that many of these themes are interconnected with one another. By specifically targeting comprehensive approaches that meet the needs of our respondents, the study suggests that rates of insurance for people under the age of 35 should increase. Further research will need to be done to assess whether the state health insurance exchanges and outreach efforts are reaching the young adult population and resulting in health insurance coverage. It will also be wise to assess whether such insurance is cost-effective, has value, and results in the use of necessary health care.
References


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