

Research Article

"The Reality of the Affordable Care Act Implementation among the Chronically Uninsured: A Qualitative Study"

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ABSTRACT

Millions of Americans remain uninsured even after implementation of the Affordable Care Act (ACA), representing a major concern for public health. Uninsured people are more likely to have more serious health problems. The uninsured are more concentrated in Medicaid nonexpansion states and the South, as well as more likely to be Spanish speaking, unmarried, and have less than a high school education. Previous research has not addressed why the chronically uninsured choose not to enroll in health insurance. This paper focuses on chronic uninsurance and decisions to sign-up for health insurance. Six focus groups were conducted with fifty-two participants during the first year of implementation of the ACA. Participants were recruited through churches, free clinics, and community centers. Seven themes emerged: immediacy, instability, personal cost, discouragement, "us vs. them", Mistrust and health insurance literacy. Themes were described through levels of the Social-Ecological model. The chronically uninsured weigh multiple factors in their decision to sign up for health insurance. Cost is a major barrier, though it is important to examine in the realm of instability and immediate needs. Future interventions should target health insurance literacy, overcoming multiple cost considerations, and skepticism toward the ACA.

Keywords: Affordable Care Act, Health Insurance, Medically Uninsured, Health Services Needs and Demands, Poverty, Health Literacy

Known

- Millions of Americans remain uninsured even after implementation of the Affordable Care Act (ACA)
- Uninsured people are more likely to have more serious health problems
- The uninsured are more concentrated in Medicaid nonexpansion states and the South
- The uninsured are more likely to be Spanish speaking, unmarried, and have less than a high school education

Information Added by this Paper

- Two themes emerged as barriers to obtaining health insurance: costs and skepticism
- Health insurance literacy was also a barrier to obtaining health insurance
- Barriers to obtaining health insurance work across all levels of McLeroy's social ecological model

Introduction

Implementation of the Affordable Care Act (ACA) contributed to approximately 11 million uninsured Americans gaining insurance. However, millions of Americans remain uninsured, a major public health concern as uninsured are more likely to have serious health problems (Decker et al. 2013). Nationally, uninsured individuals are more concentrated in Medicaid nonexpansion states and the South, and are more likely to be Spanish speaking, unmarried, and have lower education levels than insured individuals (Shartzer et al. 2014). Individuals from racial and ethnic minority groups are at a higher risk than the general population of being uninsured (U.S. Department of Health and Human Services [DHHS] 2011; DeNavas-Walt, Proctor & Smith 2011; Kaiser Family Foundation [KFF] 2-13; Doty, Rasmussen & Collins 2014).

Lack of insurance is a chronic problem, with 47% of uninsured individuals reporting five years or longer without insurance (Garfield, Licata & Young 2014). The most prevalent reasons include cost and job change or loss (Adams, Martinez & Vickerie 2010). Predictions about ACA implementation commonly cited cost as the principle barrier to accessing insurance (The Kaiser Commission on Medicaid and the Uninsured 2014). However, a study in California reported other barriers, including lack of awareness of the program or eligibility requirements, a difficult application process, burdensome documentation requirements, and literacy obstacles (Lucia et al. 2015). Related results from a Kaiser study noted that cost was not the principal reason cited for not signing up for coverage. Instead, 41% report "being told they were ineligible," although many actually appeared to be eligible. A distinction also exists between perceived costs and actual costs, as 29% reported not enrolling because of perceived high costs (Garfield & Young 2015).

South Carolina, the state where this study was conducted did not expand Medicaid, but rather, implemented a program that expanded Medicaid roles by investing in "hotspots" of poor health (Supra 2013). Uninsurance is declining, but remains higher than the national average, 15.4% vs. 11.9% (Levy 2015; South Carolina Institute of Medicine and Public Health 2014; Lopez-De Fede 2012).

Currently, individuals can sign up for health insurance through electronic or paper-based applications. They may receive in-person assistance in a variety of settings including community health centers and hospitals. According to Centers for Medicare

and Medicaid Services, "Navigators play a vital role in helping consumers prepare electronic and paper applications to establish eligibility and enroll in coverage through the Marketplaces and potentially qualify for an insurance affordability programs. They also provide outreach and education to raise awareness about the Marketplace." (Centers for Medicare and Medicaid Services 2016)

Previous research has not thoroughly addressed the specific reasons that the chronically uninsured may choose not to enroll in health insurance. The focus of this paper is to deepen knowledge on the beliefs, experiences and attempts to access health insurance among the chronically uninsured.

Methods

This manuscript presents findings from focus groups conducted as part of a larger 2014 mixed methods study in South Carolina. IRB approval was obtained prior to the study. The purpose of the study was to learn about healthcare experiences of the chronically uninsured and to determine how these experiences inform beliefs and attempts to access healthcare and/or health insurance.

Recruitment

Researchers partnered with community organizations to recruit participants. Six partner organizations in four regions worked with researchers to distribute flyers and identify potential participants. Staff used the flyers and a screening script to introduce potential participants to the project and ensure that they had been uninsured for at least three years. Participants signed up for a focus group session that was held within a 2-3 week period of recruitment. Reminder calls were made one to two days prior to the focus group session.

Data collection

Six focus groups were conducted with a total sample of 52 participants. Four focus groups were conducted in English, and two in Spanish. A detailed description of participant demographics is provided in Table 1 and in the results section.

Two trained focus group moderators conducted the focus groups and a note taker was present for each group. Each discussion was audio-recorded and transcribed by a professional transcriptionist. A 20-question semi-structured discussion guide, developed with input from community partners, was used to elicit descriptions of participants' experiences. Participants were queried about experiences seeking health insurance and healthcare in the past and through the new ACA marketplace, factors that contribute to not having health insurance, health status and health needs, and support for meeting their healthcare needs and those of others. Each focus group lasted one to two hours, and participants received a small honorarium.

Data analysis

Focus group transcripts were reviewed by each moderator to address missing data or errors. Data analysis was completed by two moderators and a third team member. A grounded theory approach was used to identify themes and an inductive narrative approach for data analysis (Bradley, Curry & Dever 2007). Researchers created a codebook, which was expanded as the research team completed open coding on all transcripts followed by axial coding for a subset of codes related to health insurance acquisition experience. Following a process detailed by Miles and Huberman, each transcript was coded by two independent coders (1994). The team met to address consensus, update the coding structure and revisit any previously coded text when necessary. This process yielded 77.81% agreement. Codes were applied to the transcripts using NVIVO 10.1.0 software (QSR International 2014). Themes emerged during a subsequent review and analysis of code-based queries. Researchers recognized that coded text was occurring across an ecological framework (McLeroy et al. 1988; Golden & Earp 2012; Glanz & Bishop 2010). Therefore, a subsequent round of coding was done to identify theme representation within each level of the ecological model. As a thematic category, health insurance acquisition occurred in 11 of 27 open or initial codes.

Results

Table 1 provides the demographics of focus group participants.

The age range was 20-68 years, and mean age was 42.5 years. A majority was African American and female, and all participants had been uninsured for three or more years. Three focus groups were conducted with individuals in rural areas and three groups in urban areas in South Carolina.

Seven central themes emerged: health insurance literacy, immediacy, instability, personal cost, discouragement, "us vs. them" and Mistrust. Six of these themes clustered into two separate categories. Immediacy, instability and personal cost clustered within a category of tangible influencing factors related to "Costs." Discouragement, "us vs. them", and Mistrust clustered into a category of psychosocial influencing factors labeled "Skepticism."

Health insurance literacy

Health insurance literacy included participants' generally low health literacy, inability to understand health insurance plan differences, or lack of skills to register or seek assistance from navigators. There was much uncertainty about eligibility, understanding plan options, and how to find information and navigate the website. Some participants sought out assistance from navigators or hospitals, many unsuccessfully.

Table 1: Focus Group Demographics (N=52).

	n	%
Race/Ethnicity		
• Non-Hispanic White	17	32.6
• African American	24	46.1
• Hispanic	11	21.1
• Other	0	0
Age (Mean, Range, yrs.)	42. 5 (20-64)	-----
Sex		
• Male	12	23.1%
• Female	40	76.9%
Years without insurance (Range, yrs.)	(3-25)	----

Participants reported reliance on local media or word-of-mouth from others who had attempted to sign up for health insurance. There was a perception that the website was designed for people in the health professions or who had health knowledge, not for "people like us."

Costs

Three themes related to cost were identified, providing a more nuanced view of how cost and factors contributing to one's ability to afford health insurance influence insurance decisions. These included immediacy, instability, and personal costs.

Immediacy

Participants described making decisions about immediate bills; if they were not currently sick, they did not see the benefit of enrolling in health insurance, as the penalty ($95) is lower than monthly premiums.

Instability

Job loss, seasonal work, divorce, relocation, injury leading to job loss, negative life events (e.g. catastrophic illness) were all described in terms of how these life events had contributed to financial instability and/or associated health insurance access instability. Several participants previously had insurance, but lost coverage when their employment situation changed and were not able to afford independent coverage.

Personal Cost

There were more than twice as many codes for personal cost than for any other theme. This was the main reason for not having health insurance in the past and for not enrolling in ACA insurance during the first year of implementation. Participants reported that they must weigh multiple priorities, including home, food, utility bills, and previous health bills; they felt that premiums were too high and feared "spiraling downward" due to debt.

Skepticism

Participants described interactions and stories that contributed to a sense of skepticism regarding signing up for health insurance (ACA). Themes include discouragement, "us vs. them" and Mistrust.

Discouragement

Participants described how previous attempts to register for health insurance and not qualifying led to discouragement and a "why bother" attitude. For those who tried to enroll through the ACA or knew others who had, high insurance costs and/or difficulty signing up or accessing information led to feelings of resignation.

"Us vs. Them."

There was a prevalent theme of us (uninsured) versus them (government or other organizations). Participants grouped trying to enroll in ACA with previous experiences of being turned down for disability, denied for Medicaid, etc., and saw this as another example of government "piling on" by penalizing the poor. They felt that the state had expanded Medicaid, but not to everyone "like us." However, at least one respondent reported receiving help from a local federally qualified health center.

Mistrust

Participants reported skepticism and uncertainty as to the source of information, and an unwillingness to release personal information.

Table 2 provides samples of focus group responses.

Discussion

McLeroy's social ecological model is used to understand and address health issues, and is widely recognized as an appropriate lens for addressing behavior change (1988). It emphasizes the reciprocal relationship between five levels of influence: individual, interpersonal, community organizations, environment and policy (McLeroy et al. 1988; Golden & Earp 2012; Glanz & Bishop 2010) (Figure 1).

The research team independently coded the text within each theme to determine the fit across each level of the Social Ecological model and to identify the origin(s) for each theme.

Health insurance literacy, immediacy, instability and personal cost mainly originated in the individual level, but cut across the remaining levels. Participants also described family events (interpersonal) that contributed to these themes. For instance, participants described immediate needs that might preclude them from paying monthly insurance premiums and thus they had chosen to accept the penalty set by the federal government under the ACA (policy).

Discouragement, "us vs. them" and mistrust were all mentioned as originating as community/organizational level factors that stretched across individual and interpersonal levels. "Us vs. them" originated in the community/organizational level but stretched all levels. For instance, participants described how employers used government and ACA rules to keep workers' number of hours just below the threshold required for health insurance benefits. This perception may be grounded in fact; a recent survey found that 20% of small employers had plans to adjust employee hours so that fewer qualified for insurance (Mkrvicka et al. 2013).

Mistrust was seen as originating in the community/organizational level, but spanning to the individual level. Participants described the personal feelings of mistrust from having unknown individuals (navigators or salesmen) come into the community. This mistrust echoes the skepticism often experienced in community-based participatory research projects (Christopher et al. 2011; Christopher et al. 2008). Health insurance navigators and other community organizations may benefit from recognizing the skeptical attitude among those they are attempting to serve. Participants also commented, even if health insurance was affordable, they were distrustful of its specific coverage.

While cost may remain a major barrier to many uninsured participants after implementation of the ACA, there are still other contributing issues. It is important to examine cost relative to instability and immediate needs; participants who may have never held health insurance in the past viewed enrolling in ACA as one more bill they could not afford, rather than a necessity. The Kaiser study found that 32% of survey respondents chose their plan because of its range of benefits or a specific benefit,

Table 2: Selected Quotes from Focus Groups.

Themes	Focus Group Responses
Health Insurance Literacy	The hospital tries to be pretty good about pamphlets and stuff when you go in for certain conditions and stuff like that, but like, most of us in the community who don't understand are not going to read it.
	…so say if someone like me that I'm a little not knowledgeable on what I'm looking at on the screen and you got all these questions and all this stuff, so maybe what I'm answering is not really correct for me, maybe I'm not understanding the questions. …when you're in the healthcare field and you understand things, you're able to understand what they're saying, but if you're not making it for the average Joe who's not in the medical field or don't understand those terms then are you answering it…
Costs Immediacy	So, are we going to have insurance or pay our power bill?
	But you, if I take out insurance on her, that means I can't pay my light bill this month, so it comes down to do you want food on the table, do I want health insurance for her, or I can't afford the light bill, I can't afford the grocery bill, can't afford anything. You want it all, but you just can't have it.
	…you have a spouse, they're able to get insurance with their job that's a certain price, but when you add family members, it becomes extremely expensive and now you have to choose between health coverage or food and clothes for your kids. So, now you're, well, I'm not going to do that because I know we need food and I know we need clothes cuz that's everyday things. I'm not going to go to the doctor every day. I might see the doctor once a year, every six months, so that extra $300 that he's spending per pay period is a lot…
	Well, we worked seasonal, so when we get out in May, if we don't continue with the job, then our insurance stopped, but then we go back, it's a, it's a time limit where we sign up for it, and if we don't sign up within that time limit, we have to wait.
Instability	I do not presently have health insurance because I work, my jobs have been jobs with grants and when my grants end everything ends, and like she said, they offer you incentive to continue your insurance, but when you have been unemployed, you've just been, your job has ended, you don't have the funds to purchase insurance.
	That's the bad part about it. He had Medicaid at the time, but certain things Medicaid don't pay for so it falls on me.
	And they don't tell you they don't pay for them they let it fall on you because this specific one was for my daughter and this one was over $1000, so I'm left to pay with that, I mean to deal with that.
Personal Cost	My niece was more injured, but even with more coverage, the cost were more than $500,000 and my sister had to keep moving around, because the charges keep following her.
Skepticism Discouragement	Then you see all this discouragement going on so it keeps others from wanting to go apply because they know what's the point.
	Yea, I been down there [community organization that assists with insurance enrollment] about three times. Every time it's the same ol' thing, so I just get tired of going.
	Hispanic non-citizens describe what they had heard from other citizens:
	My friend was eligible in a certain category, but didn't qualify because of his income. He made too much money to get the free insurance, but the insurance that he was eligible for was so expensive that he could not afford it. He tried to apply on-line and couldn't apply on-line. He went to get help with the application and based on TV ads and thinking that he would eligible, he canceled his work insurance. After finding out that he couldn't afford what he was eligible for, since he was the one that dropped the work insurance, he could not get it back.
	And they'll send you to Medicare, Medicaid, but because South Carolina did not extend its Medicaid, yea we did not extend Medicaid to certain people like us, um, so, I guess Obamacare was looking for Medicaid to catch us and South Carolina dropped us.
Us vs. Them	Cuz I'm gonna tell you, I'm a little skeptical about giving out a lot of my personal information especially when it's an organization and you see a sign on the side of the road that was a number and it says, "Call us and we'll help you with the Affordable Care Act application" and you don't know where the person is or they call you on the phone and you don't know who they are, but they want to ask you all this personal information.
Mistrust	A lot of the people want to know whether it's legit or, you know, whether it's going to cost a whole lot or whether it'll be a flim-flam or whatever, you know, especially with people coming around talking about insurance.

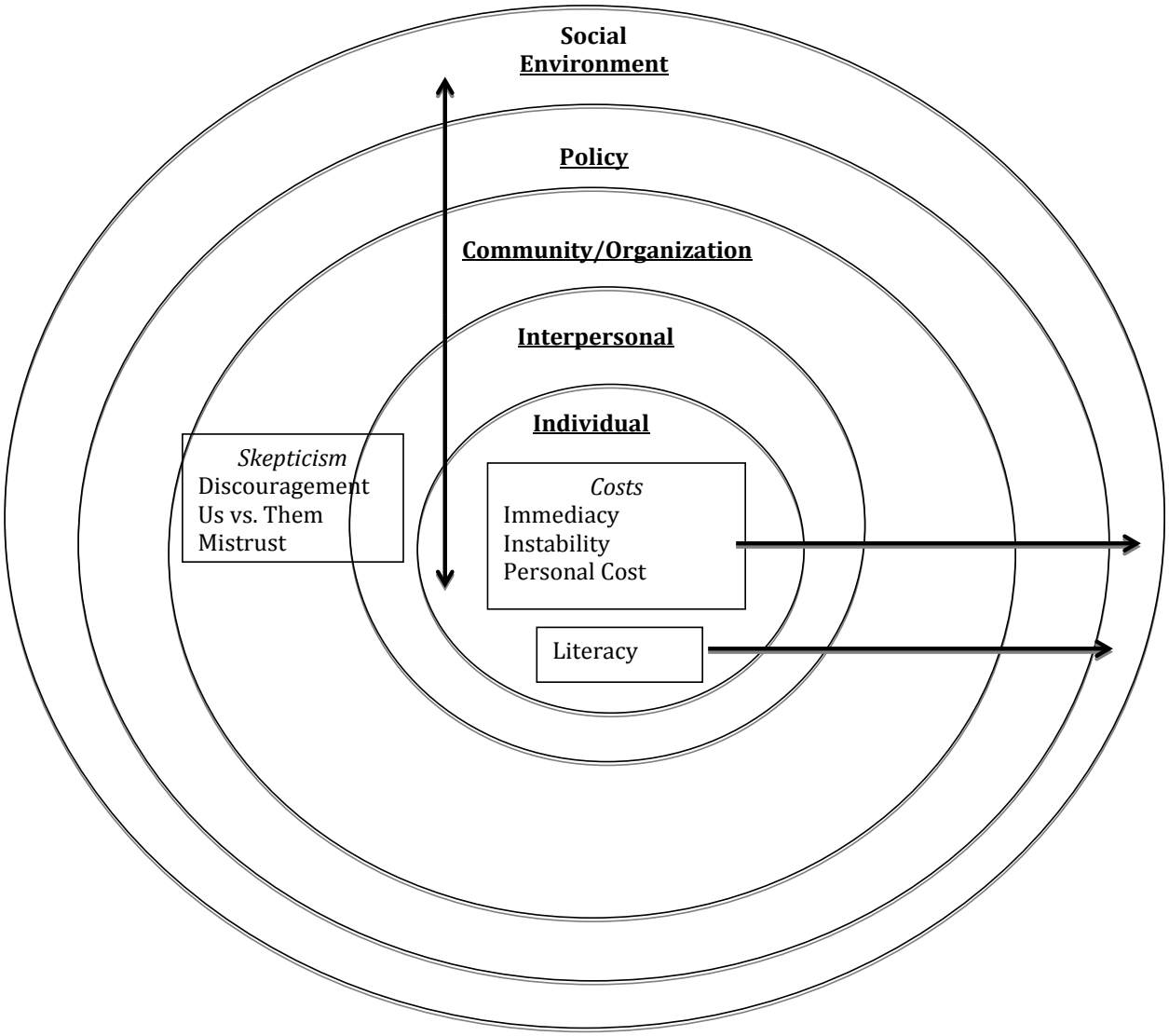

Figure 1: Social Ecological Model Adapted from McLeory, et al. (1998).

surpassing 29% who made the decision because of low cost (Garfield, Licata & Young 2014).

The research team noted the following explanatory model to describe the factors related to a decision to enroll in health insurance: (Figure 2).

This model shows how individual level factors of health literacy, immediacy, instability and personal cost contribute to larger feelings of discouragement, "us vs. them" mentality, and mistrust. These community/organizational level factors then contribute to the decision to enroll or not enroll in health insurance either in the past or currently through the ACA.

These findings show cost is one major issue, but it is not the only issue affecting the decision to enroll in health insurance. Furthermore, cost is a complex influencing factor, frequently described within the context of making decisions affecting other areas of life.

Many of these factors appear to be modifiable. If health literacy stops someone from enrolling in health insurance, then tailored interventions addressing health literacy across levels may be warranted. Factors related to wariness and cost will require community attention to social determinants of health.

This study had several limitations. While data from this formative research cannot be generalized to other populations, this study population is a fairly representative cross section of the chronically uninsured in this state. Because of the exploratory nature of this study, focus groups were not stratified by age, gender or geographic location. These factors might contribute to different experiences, although findings were remarkably similar across all six groups. The use of focus groups in this study allowed researchers to probe specific examples of factors related to the decision to enroll in health insurance and how these decisions affected health behaviors and seeking of health care services

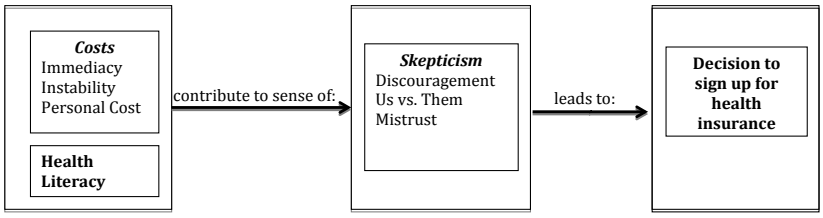

Figure 2: Explanatory Model for Decision to Sign Up for Health Insurance.

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REFERENCES

1. Adams PF, Martinez ME and Vickerie JL (2010) *Summary health statistics for the U.S. population*, Washington D.C.
2. Bradley EH, Curry LA and Dever KJ (2007) 'Qualitative data analysis for health services research: developing taxonomy, themes, and theory', *Health Services Research,* 42 (4):1758-1772.
3. Centers for Medicare and Medicaid Services. [Internet]. Baltimore: Insurance Assistance in the Health Insurance Marketplaces; 2016. CMS. Available from: https://www.cms.gov/cciio/programs-and-initiatives/health-insurance-marketplaces/assistance.html
4. Christopher S, Saha R, Lachapelle P, Jennings D, Colclough Y, et al. (2011), 'Applying indigenous community-based participatory research principles to partnership development in health disparities research', Family & Community Health, 34 (3):246-55.
5. Christopher S, Watts V, McCormick A, Young S (2008) 'Building and maintaining Mistrust in a community-based participatory research partnership', American Journal of Public Health, 98 (8):1398-1406.
6. Decker SL, Kostova D, Kenney GM, Long SK (2013), 'Health status, risk factors, and medical conditions among persons enrolled in Medicaid vs uninsured low-income adults potentially elligible for Medicaid under the Affordable Care Act', JAMA, 309 (24):2579-86.
7. DeNavas-Walt C, Proctor BD and Smith JC (2011), Income, Poverty, and Health Insurance Coverage in the United States: 2010, U.S. Census Bureau, Washington, DC.
8. Doty M, Rasmussen P and Collins SR (2014), Catching Up: Latino Health Coverage Gains and Challenges Under the Affordable Care Act, Commonwealth Fund, Los Angeles.
9. Garfield R, Licata R and Young K (2014), The Uninsured at the Starting Line: Findings from the 2013 Kaiser Survey of Low-Income Americans and the ACA, Kaiser Family Foundation, Washington, DC.
10. Garfield R and Young K (2015), Adults who remained uninsured at the end of 2014, Kaiser Family Foundation, Washington, DC.
11. Glanz K and Bishop DB (2010), The role of behavioral science theory in development and implementation of public health interventions', Annual Review of Public Health, 31 (1):399-418.
12. Golden SD and Earp JA (2012), 'Social ecological approaches to individuals and their contexts: twenty years of health promotion interventions', Health Education & Behavior, 39 (3):364-72.
13. Kaiser Family Foundation (2013), Uninsured rates for the nonelderly by race/ethnicity, Washington DC.
14. Levy J (2015), In U.S., Uninsured Rate Dips to 11.9% in First Quarter, Gallup, Inc. Washington, DC.
15. Lopez-De Fede A (2012), Who are South Carolina's Uninsured?, USC Institute for Families in Society, Columbia, SC.
16. Lucia L, Dietz M, Jacobs K, Chen X and Kominski GF (2015), Which Californians will lack health insurance under the Affordable Care Act?, UC Berkeley Center for Labor Research and Education & UCLA Center for Health Policy Research, Los Angeles.
17. McLeroy KR, Bibeau D, Steckler A, and Glanz K (1988), 'An ecological perception on health promotion programs', Health Education Quarterly, (15):351-372.
18. Mkrvicka N, Held J, Stich J and Kolsrud K (2013), Employer-Sponsored Health Care: ACA's Impact, International Foundation of Employee Benefit Plans, Brookfield, WI.
19. Miles MB and Huberman AM (1994), Qualitative Data Analysis: An Expanded Sourcebook (2nd Edition ed.) Sage Publications, Los Angeles, CA.
20. QSR International (2014), NVivo 10.1.0, Burlington, MA.
21. Shartzer A, Kenney GM, Long SK, Hempstead K and Wissoker D (2014), Who are the remaining uninsured as of June 2014?, Urban Institute Health Policy Center, Washington, DC.
22. South Carolina Institute of Medicine and Public Health (2014), Issue Brief: A Profile of the Uninsured in South Carolina, Columbia, SC.
23. Supra J (2013), Health Reform in South Carolina, South Carolina Department of Heatlh and Human Services, Columbia, SC.
24. The Kaiser Commission on Medicaid and the Uninsured (2014), Key Facts about the Uninsured Population, Kaiser Family Foundation, Washington, DC.
25. U.S. Department of Health and Human Services (2011), Overview of the Uninsured in the United States: A Summary of the 2011 Current Population Survey, Office of the Assistant Secretary for Planning and Evaluation, Washington, DC.

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