“It’s Like Pay Or Don’t Have It and Now I’m Doing Without”: The Voice of Transitional Uninsured Former Foster Youth

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Abstract
Twenty-four thousand American youth lose Medicaid entitlements after discharge from foster care annually. The circumstance of being uninsured is a formidable barrier to health care that leaves the youth vulnerable to unmet health care needs. Given that foster youth often develop physical and/or mental health problems as a result of abuse or neglect, continuous access to health care is especially important. This descriptive phenomenology study explores the lived experience of transitional uninsured former foster youth. Nine uninsured former foster youth were recruited from a nonprofit community organization in an urban county and interviewed using semistructured interviews. Four themes identified from the analysis were (a) “Surviving the real world”: emancipation without essential documentation; (b) “It’s not always going to be fine”: managing mental and physical health without health care insurance; (c) “Roadblocks”: barriers to securing health care insurance; and (d) “Just not knowing”: Medicaid eligible albeit without health care insurance.

Keywords
state legislation, health disparities, coverage/access, public health, federal legislation, Medicaid

Of the more than half million American youth currently in foster care in the United States, approximately 24,000 “age out” (discharged from foster care typically at age 18 or 21, depending on state policy, and no longer under the care and responsibility or supervision of the state child welfare system) every year (Freundlich, 2007). Aging out of foster care is an especially vulnerable time for foster youth. Government provided resources and services (housing, clothing allowance, personal incidentals for daily living, dental insurance, and health care insurance) are terminated after the youth leave foster care. Competing priorities and limited personal resources often leave former foster youth without health care insurance. The circumstance of being uninsured is a formidable barrier to health care for former foster youth. Given that foster youth often develop physical and/or mental health care needs as a result of abuse or neglect, continuous access to health care after discharge is especially important (Kushel, Yen, Gee, & Courtney, 2007). Although current literature depicts the problem of transitional uninsured former foster youth, little is known about how this phenomenon affects the youth from their perspective.

Background
Through no fault of their own, youth are thrust into foster care, typically because of parental or guardian child abuse or neglect. Youth who are removed from their homes are placed for 24-hr care in foster family homes, institutions, or group homes by the state child welfare agency (foster care). Placement is determined by a court or by a voluntary placement agreement between the state and the youths’ parent or legal guardian (Fernandes-Alcantara, Szymbenda, & Stoltzfus, 2011). State welfare agencies use federal and state dollars to pay for youth in foster care and provide assistance to those who are likely to age out. Youth transitioning from foster care to independence face many challenges (Hunter, 2011; Samuels, 2008; Wolanin, 2005). Research suggests that former foster youth are at risk for poor education, employment, housing, and health outcomes. Multiple moves in foster care jeopardize educational status, resulting in foster youth frequently falling one or more years behind in educational progress (Wolanin, 2005). Only 50% leave foster care with a high school diploma or General

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Educational Development, a significant predictor of income in adult life, compared with 70% of their nonfoster youth peers. Although 70% of their nonfoster youth peers enter postsecondary training, only about 20% of college-prepared foster care alumni enter postsecondary training and completion rate studies indicate that less than 10% graduate. Among the many mitigating factors against degree completion by former foster youth are lack of family support, no home base, and poverty.

The number of youth leaving foster care without a permanent family is at an all-time high (Freundlich, 2007). The loss of their biological family, essentially the loss of a home, leave former foster youth with social support needs (Samuels, 2008). Positive family or family-like relationships of discharged foster youth are the strongest predictor of stability and economic independence in adulthood (Freundlich, 2007). Without a support network, discharged foster youth do not fare well as young adults (Samuels, 2008).

Fifty-one percent of discharged foster youth experience unemployment within 2 to 4 years of discharge (Mosqueda & Rodriguez, 2005). Sixty percent of former foster youth earn incomes at or below US$ 6,000 per year, substantially below the federal poverty level (Pierce & Brooks, 2003).

Former foster youth who left care by age 18 are nearly three times more likely than their nonfoster youth peers to be out of work (Lorentzen, Lemley, Kimberlin, & Byrnes, 2008). Unemployed former foster youth face increased risk of unstable housing and homelessness (Kushel et al., 2007). Former foster youth are twice as likely to be unable to pay their rent and are four times as likely to be evicted. Within 18 months of discharge 40% to 50% of former foster youth become homeless (Juvenile Justice Study Committee, 2002). Unstable housing status of former foster youth is a predictive factor of worsening health care insurance coverage and unmet health care needs (Kushel et al., 2007).

Foster youth transitioning from foster care to independence have disproportionately high rates of physical and mental health problems compared to their nonfoster youth peers (Kushel et al., 2007; Rest & Watson, 1984; Schor, 1982). Nearly 50% of foster youth suffer from chronic conditions such as asthma, cognitive abnormalities, visual and auditory problems, dental decay, and malnutrition (CCS Partnership, 2011). Foster youth are more likely than their nonfoster youth peers to have birth defects, developmental delays, or emotional and behavioral problems and more than 50% require ongoing medical treatment (CCS Partnership, 2011). Eighty percent of foster youth have received services for a mental health condition at least once in foster care (Lopez & Allen, 2007). Foster youth are three times more likely to suffer from depression than their nonfoster youth peers and experience posttraumatic stress disorder at a rate two times the level of U.S. war veterans (McMillen et al., 2005). These conditions stem from exposure to alcohol and drugs, poor parenting, lack of medical care, domestic violence, neglect and abuse, and unstable living conditions prior to removal by the state (Schor, 1982). The trauma of family separation, frequent moves, and the stress and disruptions brought about by impermanent placements in the foster care system worsens their situation.

Over the last 25 years, legislators and policy makers have recognized the challenges for foster youth and targeted legislation to address some of the key challenges (Hunter, 2011). In 1999, the Federal government acknowledged the poor outcomes of discharged foster youth and enacted significant legislation to support the needs of former foster youth (Foster Care Independence Act, 1999). The John H. Chafee Foster Care Independence Program (CFCIP) was established to help current and former foster care youth achieve self-sufficiency. CFCIP serves (a) youth who are likely to remain in foster care until age 18; (b) youth who, after turning 16 years of age, have left foster care for kinship guardianship or adoption; and (c) young adults, ages 18 to 21, who have “aged out” of foster care. Grants are offered to states to assist former foster youth with postsecondary education, employment, financial management, and housing (U.S. Department of Health and Human Services, 2011). CFCIP also allows states discretionary extension of Medicaid coverage to former foster youth between ages 18 and 21. Despite Medicaid’s health care advantage for youth in foster care, only 17 states had implemented the extension by 2007, leaving 25,000 former foster youth without Medicaid annually (Child Information Welfare Gateway, 2009).

The most prevalent health care access problem identified by foster youth transitioning to independence are lapses in health care insurance (Raghavan, Shi, Aarons, Roesch, & McMillen, 2009). Raghavan et al. examined former foster youth who have lost Medicaid entitlements and their ability to acquire employer-sponsored or student health care insurance coverage after discharge. Raghavan and colleagues posited that employment and college or university status would reduce transitional time to first insurance loss. Only 50% of youth interviewed were able to find employment. Employment was a predictor of insurance coverage but student status was unrelated. Most former foster youth were unable to secure health care insurance after leaving foster care in the 2-year follow-up study. The 17% of participants who did regain health insurance did so after an 8 month transitional period without coverage. Former foster youth without health care insurance are 50% more likely to lack regular health care than their nonfoster youth peers which leads to a 10-fold increased risk of hospitalization, decreased rates of vaccinations, check-ups, and follow-up care (Sommers, 2005). In a systematic literature review, Lopez and Allen (2007) identified health care needs of former foster youth in the primary care setting. A transitional plan was recommended to facilitate better health outcomes of discharged foster youth:

1) assessing health care needs; 2) providing care coordination; 3) increasing the adolescent’s knowledge of their health conditions and ability to problem solve health care issues; 4) assisting the adolescent in accessing health insurance; 5) setting up community services—employment, housing, education through
social work; and 6) identifying an adult primary and specialty provider for continued health care. (p. 1)

Despite the relevant quantitative works, case study and legislative initiatives supporting the import of continuous health care insurance coverage at discharge, foster youth continue to transition out of foster care without health care insurance coverage (Hunter, 2011).

**Purpose**

Little is known about the hardships of being uninsured from the perspective of transitional foster youth as they attempt to be self-sufficient after discharge. No evident phenomenological work captures the lived experience of uninsured former foster youth transitioning from foster care to independence. This study explored the lived experience of transitional uninsured former foster youth.

**Method**

A descriptive phenomenological approach was selected for this study because the method provided thick, rich descriptions of the experience of transitioning uninsured former foster youth, which facilitates an understanding of the phenomenon. Husserl’s philosophical ideas provided the underpinning for the phenomenological enquiry (as cited in Spiegelberg, 1982). Husserl believed subjective information is important in seeking to understand human motivation which is influenced by what people perceive to be real. The subjective experience of former foster youth transitioning from foster care to independence without health care insurance was the focus of this study. The particular method selected for phenomenological analysis was derived from the procedural steps outlined by Colaizzi (1978).

**Setting and Sample**

All research study procedures were approved by the University’s Institutional Review Board (IRB). Purposive and snowball sampling was used to recruit transitional uninsured former foster youth through a social service outreach program which assists former foster youth transitioning from the foster care to independence in an Indiana urban county. The program provides direct services to approximately 25 former foster youth but serves a total of approximately 700 former foster youth through contracted service providers. Within the population of 700, 75% are African American, the average age is 17.5 years with a 40:60 male to female ratio (S. Criss, personal communication, December 16, 2010). Participants met the following inclusive criteria: a self-reported former foster youth discharged no more than 1 year from foster care, greater than 18 years of age, English speaking, and without any form of health care insurance within the last 12 months.

**Data Collection**

Nine participants were interviewed individually over a 3-month period. A semistructured, two-part interview was used to preserve the gestalt of the lived experience of each participant and their collective experiences (Holloway, 2005). In the first part, the interviewer used an approach of noninterruption to ask the participant to “Please describe your story or experience of being a transitional uninsured former foster youth?” to elicit concrete events. Using the ordering and language presented by the participant in the first part, reflexive, pragmatic semistructured questions were asked in the second part such as “You had mentioned that you were trying to get Medicaid right now. How has that process been?” and “You told me earlier that you started to cut yourself in the hole [solitary confinement] and then you got discharged [from foster care], were there times after discharge or now that you want to cut yourself?” and “Were you able to pay off your bill from the last hospital visit?” The interviews lasted between 16 and 46 minutes each, all were digitally-recorded and transcribed.

**Data Analysis**

An adaptation of Colaizzi’s (1978) descriptive phenomenological method was used to develop an essential structure of the phenomenon. This aim was accomplished by (a) obtaining a sense of each interview as a whole experience by listening to the audiotaped interviews exhaustively and reading the transcription of each participant’s interview; (b) extracting significant statements from the transcript that pertained to the investigated phenomenon: transitioning uninsured former foster youth experiences; (c) formulating meanings from significant interview statements (verbatim quotes); selected examples of significant statements and corresponding formulated meanings are listed in Table 1; (d) organizing the formulated meanings into themes that transcended through the different experiences and concrete occasions described by the participants (Table 2) (Holloway, 2005); (e) comparing the theme clusters to the original descriptions to validate the cluster and to examine discrepancies; (f) integrating the essential structure of the lived experience into a description of the phenomenon under study: transitional uninsured former foster youth lived experiences (Table 3); and (g) asking the participants to read the interview transcripts to assure that it faithfully represented their experience as a measure of trustworthiness of the research findings.

**Methodological Rigor**

Several steps were taken to ensure trustworthiness (Lincoln & Guba, 1985). Credibility was demonstrated by: member checks (asking study participants to review transcripts for accuracy) and peer debriefing (discussing data collection and analysis with coauthors). Dependability was assured by
use of bracketing and an audit trail. Husserl’s method of bracketing was used during the subjective process of the descriptive analysis (as cited in Spiegelberg, 1982). Bias and prejudice were suspended by bracketing author presuppositions. The audit trail provided explanations of how the data was collected and analyzed. Transferability was established by use of thick descriptions of the participant’s interviews, to communicate to the reader a realistic picture of the phenomenon. Direct quotes from the research study participants were implemented in the results section to strengthen the transferability of the research.

Results
The final sample size, determined by saturation of themes, included nine transitional uninsured former foster youth, five males and four females (five African Americans, two White, one Hispanic/Latina, and one self-identified “Other”).

Table 1. Transitional Uninsured Former Foster Youth Phenomena: Selected Examples of Significant Interview Statements and Corresponding Formulated Meanings

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<th>Significant Interview Statements</th>
<th>Formulated Meanings</th>
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<td>“The fall of my 18th birthday . . . I didn’t have anything. I didn’t have my birth certificate. I didn’t have my social security card. I didn’t have a Medicaid card . . . medicine to help me concentrate, depression medication . . . When I left, they didn’t give me any of that . . . So thinking back on it now, that could of been really bad for me . . . just a horrible outcome . . . and I’ve been without insurance since . . . It’s not always going to be fine . . . You need all that to survive in the real world.” (Nicole)</td>
<td>Emancipated foster youth often leave the child welfare system unprepared for independence and are expected to be self-sufficient and apply for publicly funded health care insurance</td>
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<td>“When I turned 18, I was released . . . pretty much with nothing . . . I had no place to stay, nobody’s house or nowhere to go and they released me like that on my 18th birthday. They just said it’s time for you to go and that was that. They don’t really help you when you really need help the most.” (Derek)</td>
<td>The transition from the child welfare system to independence has many barriers to securing health care insurance</td>
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<td>“I got denied (health care insurance) because of residency (otherwise homeless on-campus college student) . . . I talked to the registrar, ‘I need a simple letter saying that . . . I’m on campus and I go to school full-time . . . I just need proof’ and I guess that wasn’t accepted.” (Nicole)</td>
<td>Uninsured former foster youth often go without lifesaving health care and medication for their physical and mental health because of inability to pay for health care and medications</td>
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<td>“I haven’t had any real treatment for the past year . . . it’s real bad. I go up the stairs . . . twelve steps and I’m out of breath.” (Derek)</td>
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<td>“I couldn’t breath . . . I felt like I was suffocating . . . I would need my inhaler . . . I would . . . just push through it.” (John)</td>
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<td>“I knew . . . it was in my best interest to get back on Prozac but I didn’t have the right help or guidance I needed . . . I don’t think that there is any kid in foster care that hasn’t thought of suicide . . . especially if you grew up in a troubled home. I’ve thought of it several times.” (Carie)</td>
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<td>“I just feel like there is no point in taking medicine that is supposed to extend my life if I’m thinking about ending it.” (Chris)</td>
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<td>“biggest roadblock . . . not knowing” (Paul)</td>
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<td>“No One Explained” (Carie)</td>
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<td>“I had health care insurance until age 19 . . . but I didn’t realize it. I went to apply for food stamps and they told me about it . . . I thought it was for old people.” (Chris)</td>
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Table 2. Transitional Uninsured Former Foster Youth Phenomena: Theme Clusters

<table>
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<th>Clusters of Themes</th>
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<tr>
<td>Uninformed regarding eligibility of health care insurance ages 18 to 21 with no renewal before discharge</td>
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<tr>
<td>Expectations</td>
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<tr>
<td>Managing with few resources and documentation after emancipation</td>
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<tr>
<td>Potential for bad mental/physical outcome after emancipation</td>
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<td>Roadblock</td>
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<tr>
<td>Fostering experience</td>
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<tr>
<td>Mistrust/suspicion</td>
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<tr>
<td>Foster youth stereotypes</td>
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<tr>
<td>Collateral damage of foster care</td>
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<tr>
<td>Made it against all odds and wanting to give back to other foster youth to make a difference</td>
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Participants were aged 18 to 22 and within a self-reported 1 year of state funded program eligibility services for former foster youth. There were no marked differences in the findings between gender, or among ethnicity or age. An exception was a female’s perspective that former foster youth who become pregnant are “rewarded with health care insurance” (Nicole).1

Several notable themes emerged from the data (Table 2); however, this analysis centered on the structure related to experiences with no health care insurance. The transitioning former foster youth were unaware of their Medicaid eligibility and reported many barriers in reenrolling for Medicaid and/or securing other health care insurance coverage. Being uninsured led to limited or no access to health care services, frustration, and suboptimal health status. Four theme clusters were identified from the analysis: (a) “Surviving in the real world”: discharged without essential documentation; (b) “It’s not always going to be fine”: managing physical and mental health without health care insurance; (c) “Roadblocks”: barriers to securing health care insurance; and (d) “Just not knowing”: Medicaid eligible albeit without health care insurance (Table 3).

**Theme 1: “Surviving in the Real World”: Discharged Without Essential Documentation**

For many of the former foster youth, essential documentation to secure health care insurance was not made available to them at the time of discharge from foster care. Most were discharged without a birth certificate, social security card, and a short-term or permanent living plan (an address). Without the referenced documentation at discharge, the former foster youth were unable to successfully reapply for Medicaid. The documentation and information required to apply for Medicaid in the state of Indiana include (a) record of social security number, such as social security card; (b) record showing age, such as birth certificate; (c) household address; (d) phone number; (e) bank statement; and (f) record of income (Indiana Family and Social Services Administration, 2010).

Participants described the lack of material resources provided on their day of discharge:

<table>
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<th>Themes</th>
<th>Essential Structure</th>
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<tr>
<td>Discharged without essential documentation</td>
<td>Unrealistic expectations of transitional uninsured former foster youth applying for publicly funded health care insurance</td>
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<tr>
<td>Managing physical and mental health</td>
<td>Colossal potential for sentinel outcomes of transitional uninsured former foster youth</td>
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<tr>
<td>without health care insurance</td>
<td>Transitional uninsured former foster youth are vulnerable populations that encounter unique barriers to obtaining health care insurance at one of the most vulnerable times of their lives, often leaving the uninsured foster youth with unmet health care needs</td>
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<tr>
<td>Barriers to securing health care insurance</td>
<td>No renewal of current Medicaid before emancipation and no knowledge of continued Medicaid eligibility after emancipation</td>
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<td>Medicaid eligible albeit without health care insurance</td>
<td>The fall of my 18th birthday . . . I didn’t have anything. I didn’t have my birth certificate. I didn’t have my social security card. I didn’t have a Medicaid card . . . You need all that to survive in the real world. (Nicole)</td>
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Mike recounted a similar experience of inadequate resources to be self-sufficient after being released from juvenile Department of Corrections (DOC) segregation (serving a 6 month sentence for running away from a group home in search of his family while in foster care),

And ah when I got out of there, I was seventeen and I was, it was Thanksgiving and I was going to be eighteen in January and ah [short pause] they had to have a placement for me to be able to release me. They had to have been able to check the place out and agree for me to leave, to leave. And ah, it took forever to find somebody to say I could live with them. And the thing was, when I finally did find someone to live with them, it was just literally them saying I could live with them so I can get released and then ya [/you/] know, on my own. So that’s how that went. And it was really rough. It was so hard for me cuz [/because/] ah I was alone, it was winter time, and ah I was staying in like in this mechanic shop it t t [stuttering] was shut down or whatever but I was staying there for like 3 or 4 months. An ah when I finally did turn 18, I um [short pause] I couldn’t get a job because the problem was, I didn’t have and ID, social security card or birth certificate and I couldn’t get em [/them/] until I finally found somebody with a credit card who could order my birth certificate on line from Texas.

John described his 18th birthday experience,

When I turned 18, I was released . . . pretty much with nothing . . . I had no place to stay, nobody’s house or nowhere to go and they released me like that on my birthday. They just said “yah, it’s time for you to go” and that was that.
Eight of the 9 participants spoke of being denied Medicaid after reapplying subsequent to their 18th birthday. John described his experience with reenrolling,

It’s kind of a difficult experience because I wasn’t supposed to be cut-off . . . because at the time, I was still eighteen but I was still in the foster care system . . . they hadn’t closed my case.

John further explained that he had to reenroll because of an oversight within the foster care system and the process was taking much longer than he anticipated, “I’m in the process right now . . . about six months . . . Hopefully I will have health care insurance soon.” Nicole “tried to get insurance for years”. Nicole applied for Medicaid several times and was denied every time. For an additional 3 years, Nicole sought out other third-party health insurance coverage, specifically designed for indigent patients, and became frustrated after several denials and quit trying.

Theme 2: “It’s Not Always Going to Be Fine”: Managing Physical and Mental Health Without Health Care Insurance

None of the participants regularly visited a health care provider for preventative care, health screenings or primary care. Seven of the 9 participants discussed health care insurance in terms of a means to manage only episodic physical and mental health care. Without health care insurance, reported access to health care was limited. All of the participants tried to “stay away” from health care providers and dentists because of financial constraints and their inability to pay for health care bills, even though all participants reported physical and mental health conditions.

Several physical health conditions were mentioned by the participants. Three participants disclosed having asthma. John reported at least three episodes daily of asthma related shortness of breath. Mike, also with asthma, stated he had untreated gastric reflux that causes daily episodes of nausea and vomiting. Carie reported she has frequent migraines and untreated gastric reflux that causes daily episodes of nausea and vomiting. Mike, also with asthma, stated he had untreated gallbladder disease (cholelithiasis) and that she was advised to have her gallbladder removed. Chris was recently diagnosed with HIV and presently he is not being treated. Nicole stated that she menstruated only twice last year (oligomenorrhea), and was managed with birth control pills (oral contraception) but “couldn’t keep up with it” because “money is so tight” and shared “I could sure use insurance right now.” Sara reported that a 2 year history of an untreated rash caused her job to be terminated.

All of the participants reported mental health conditions. Interestingly, 6 participants stated they were diagnosed with either attention deficit disorder (ADD) or attention deficit hyperactivity disorder (ADHD) while in foster care and each of those 6 participants believed their inability to focus was a function of their environment, not a result of a neurological cognitive disorder. Four participants reported a formal diagnosis of depression by a mental health provider and 2 additional participants had self-reported depression with 5 participants detailing past suicidal ideations. Of the participants with depression, 3 reported a diagnosis of bipolar affective disorder. Another 2 participants stated they were treated for anger management while in foster care.

Other than Sara’s 10-day supply of antibiotics that were finally prescribed by an emergency department provider for her rash of 2 years, none of the participants’ physical or mental health conditions were being treated or managed by a health care provider.

Health care is really important . . . there was plenty of times when . . . I had to make a decision whether I would actually . . . pay my bills this month, should I be without a phone with no contact information or ya [/you/] know anything or do I go see my doctor. I have always had health care concerns that I wanted to get checked out. (Mia)

Paul described an experience with an acute illness, “I was really sick” but left the provider’s office without the expensive antibiotics because of “no money.” Although the participants were able to capitalize on accessible resources, that is, headache, antacid and other over-the-counter medicines, to manage their mental and physical health without health care insurance, potential life-saving interventions and medications were inaccessible due to financial constraints and lack of health insurance coverage. Carie remarked, “It’s like pay it or don’t have it and right now I’m doing without.” Derek with asthma reported,

I haven’t had any real treatment for the past year . . . it’s real bad. I go up the stairs . . . twelve steps and I’m out of breath . . . I’m a very active person . . . I love to play football, basketball and all of that . . . It’s just hard to keep up without needing to take a break . . . or use of my inhaler . . . I had to buy it from [a large retailer] . . . It’s not even a prescription . . .

Later Derek confirmed that the over-the-counter inhaler referenced was an epinephrine inhaler. Derek also added “it’s about thirty dollars . . . that’s a lot of money . . . I try not to be as active as I want to be.” John, also with asthma, described an acute asthma attack experienced without a rescue inhaler, “I couldn’t breathe . . . I felt like I was suffocating.” John later shared a means of managing asthma exacerbations, “I . . . just push through it.”

Many participants spoke of their depression as collateral damage of foster care. “I don’t think that there is any kid in foster care that hasn’t thought of suicide . . . especially if you grew up in a troubled home. I’ve thought of it several times” (Carie).
Without health care insurance, the participants were not seeking mental health care or acquiring their mental health medications. Commenting about her depression, Carie said, “I knew . . . it was in my best interest to get back on Prozac but I didn’t have the right help or guidance I needed.” Chris, diagnosed with bipolar affective disorder, recounted his experiences from foster care and described the circumstances that led to his HIV diagnosis,

“I’ve been in foster care since birth. There was a brief couple of years that my biological mother had her rights but she messed it up again . . . before . . . eight years old, I had to have had like twenty different foster homes . . . I was diagnosed with HIV in 08 . . . I guess I didn’t have the upbringing to know any better about the stuff that I was doing so I made dumb decisions.

Chris described participating in a state funded HIV program that provided medicine,

“All I can do is get my medications . . . I don’t actually get like regular doctor check-ups . . . I don’t get labs drawn as regular as anybody else would so I’m lacking in a lot of things.

Chris followed that by saying the HIV medication “side effects . . . were not completely explained” and he thought that he had “actually been suffering from . . . side effects.” Chris really wanted to seek counsel from a mental health care provider “to talk to him” regarding his suicidal thoughts.

“I was thinking about going to [a Mental Health Facility]. I know that they have counseling and things but then again . . . insurance” (Chris).

Due to financial constraints, Chris never consulted a mental health care provider regarding the HIV medication side effects. Consequently, 2 months prior to the research study interview, he discontinued life-saving HIV medication for a concern of a suicidal ideation side effect and confessed, “I just feel like there is no point in taking medicine that is supposed to extend my life if I’m thinking about ending it.”

Chris referenced circumstances that prompted workers from foster care to intervene and her subsequent untreated depression and stress,

The reason why I had to be in foster care is because when I was born, my father committed suicide and my mother sold me on the street as a prostitute and didn’t feed me and locked me in closets so CPS took over . . . And I’ve had no contact with my mother other than in like 4th grade. I got a letter from her and it had settled just different things like, “I love you and I’m sorry . . .” I spent 2 weeks trying to find her and found out it was a fake address which made me really depressed . . . I get flashbacks all the time . . . in my dreams, I’ll see the guys that my mom sold me to and it just scares me and I’ll wake up crying and screaming.

Nico, with ADHD and depression, stated that she had been on a medication for depression (selective serotonin reuptake inhibitor, SSRI) “for years” and that she was discharged from the group home without medication. Nicole added the statement about the abrupt discontinuation of the (SSRI), “It’s not always going to be fine . . . thinking back . . . that could of been really bad for me . . . just a horrible outcome.”

Theme 3: “Roadblocks”: Barriers to Securing Health Care Insurance

Participants described three notable clusters of barriers to securing health care insurance during the transition from foster care to independence.

Access to basic means. For many of the participants, access to basic means of living was a barrier to securing health care insurance. No permanency or place to live (no physical address), no money or credit card, no phone, and unemployment prevented the participants from applying for Medicaid or pursuing other health care insurance coverage options.

Mike, a homeless youth, was denied health care insurance for low income patients because of a requirement to provide a piece of addressed mail as proof of county residency. “Small things that people take for granted like a piece of mail . . . I can’t even go to the doctor because I don’t have a piece of mail and I don’t understand it. I really don’t” (Mike).

Inability to focus. All the participants described the inability to focus or direct attention to health care insurance needs at the time of discharge as a barrier to securing health care insurance coverage. All 9 participants commented on the imminent challenges of discharge from the foster care making the intent to secure health care insurance less important. In describing the transition from foster care to independence, Nicole was just “trying to keep on track” leading up to and following discharge.

Of course you can’t focus . . . dealing with so much . . . Being a foster youth . . . you have so much on your mind already mentally that, um, insurance is not something . . . you’re thinking about. (Paul)

Unaware of eligibility. The “biggest roadblock” was “just not knowing” about the Medicaid eligibility and the supposed family case manager (FCM) directed renewal process in advance of discharge, reported Paul. Every participant provided commentary about being uninformed about aspects of Medicaid. This profound insight led to an unexpected direction of the research study with findings that coalesced around the fourth invariant theme which addresses the unknowingly Medicaid eligibility of former foster youth who were in foster care greater than 6 months and aged out at 18 years of age.


Theme 4: “Just Not Knowing”: Medicaid Eligible Albeit Without Health Care Insurance

When the methodology of the research study was constructed, an expectation was made by the researchers that the average age of the participant would be about 21 years of age, because that was the age former discharged foster youth became ineligible for Medicaid in the state of Indiana. The researchers expected that the participants, although no longer in the physical care of the foster care system, would have had Medicaid health care insurance until age 21, when in fact, all but one did not.

No renewal of current Medicaid before discharge. Only Carie was reenrolled in Medicaid by a Family Case Manager before discharge, although all of participants met Medicaid eligibility as former foster youth in the Indiana urban county. Even though Carie was informed of continued Medicaid eligibility requirements, she was unclear about the nuances of continued services and was “never told” when her eligibility was to be terminated. The day before Carie’s 21st birthday, under the impression of being covered by health care insurance, she went to the emergency department for treatment of a severe migraine. After learning that Medicaid had already been “cut off,” Carie “didn’t know what to say or what to do” because she was in so much “pain.” She decided to stay for the treatment of her migraine and now is financially “ruined” with very poor credit because she was unable to pay her hospital bill. Carie stated that the medical debt still causes her to have significant stress and anxiety. She also shared that she continues to have serious credit problems which make it difficult to get a bank loan, save money, or pay for other basic goods and services.

No knowledge of continued Medicaid eligibility after discharge. Eight of the 9 participants were unaware they were eligible for Medicaid between the ages of 18 and 21 after discharge. Participants spoke of being uninformed of their Medicaid eligibility. The consensus was, “Once you age out, you don’t have insurance,” (Paul) and “I thought once you turned 18 that was it,” (Derek) and “I had health care insurance . . . but I didn’t realize it . . . I went to apply for food stamps and they told me about it. I didn’t know what Medicaid was . . . I thought it was for old people” (Chris). “I had been told that once I graduated from high school that I wouldn’t have health care insurance so then I was just like okay” (Mike). In addition, after learning of their Medicaid eligibility through an after care outreach program, most youth attempted to reapply for Medicaid but were reportedly denied.

Discussion

Recent research on the transition from foster care to independence in the literature underscores the challenges for former foster youth. The findings from this phenomenology study were not the exception, but this research focused exclusively on the experiences of transitional former foster youth without health care insurance. Several implications can be drawn from these interviews presented.

Health and Well-Being

This study described health care utilization by transitional uninsured former foster youth with physical and mental health care needs that could potentiate preventable sentinel outcomes, including death. Lopez and Allen’s (2007) guidelines to address the health care needs of foster youth transitioning out of foster care are not useful if health care is inaccessible to the uninsured youth. The thoughtful interventions cannot be implemented to facilitate better health outcomes if former foster youth are not seeking care, as reported in these interviews, because of a lapse in Medicaid. Bridging the health care coverage gap is essential to the health and well-being of former foster youth. Without health care insurance, participants reported limited access to health care, leaving the former foster youth at risk for adverse physical and mental health related outcomes. Derek’s use of the epinephrine inhaler is unsafe since he uses the inhaler more than “21 times a week” which is far more than the recommended usage. The epinephrine inhaler labeling recommends use for only temporary relief of occasional symptoms of mild asthma and warns the user to see a doctor if experiencing two or more asthma attacks in 1 week (Armstrong Pharmaceuticals, 2010). The label also warns serious problems associated with use, such as heart attack and stroke, that increases if used more frequently than recommended. John’s management strategy of just pushing through an asthma exacerbation is an alarming strategy, given that 4,000 people die every year from asthma related deaths in the United States, many of which are avoidable with proper treatment and care (Akinbami, 2006). Nicole was not given any medication or prescriptions for depression on the day of discharge even though a gradual tapering regimen is recommended when stopping psychotropic medicine to avoid risk of discontinuation syndrome and the associated symptoms such as dizziness, headache, nausea, anxiety, agitation, and aggressive and impulsive behaviors (Ramaswamy, Malik, & Dewan, 2005).

Expectations

There are unrealistic expectations of transitional uninsured former foster youth. According to the Department of Children Services state policy guidelines (foster care), “At age 17 years and six (6) months, the FCM will . . . send an email to Medicaid Enrollment Unit (MEU) informing them that the youth will need to be enrolled in Medicaid Foster Care Independence Program” to maintain Medicaid coverage after discharge (Indiana Department of Child Services, 2010). Neglecting to reenroll foster youth before discharge, pursuant to the Foster Care Independence Act Chafee Medicaid option, leaves the youth to transverse the much more
difficult after discharge process. Derek remarked, “They don’t really help you when you really need help the most.” Filing for Medicaid reenrollment before or after discharge can mean the difference between approval and denial. Asking former foster youth, without essential documentation, to reapply for Medicaid increases the chance for potential filing errors with a resultant risk of denial. Foster youth are inherently a vulnerable population and an expectation of the youth to apply for Medicaid in such a pivotal time in their life posits the question, are the expectations of former foster youth beyond our expectations of nonfoster youth residing in intact families?

Policy and Policy Implementation

Eight of the 9 participants were systematically denied health care insurance coverage to which they were entitled as a result of poor State policy implementation, not by means of absent Federal policy.

No knowledge of continued Medicaid eligibility after discharge. Federal policy was enacted to assist former foster youth to achieve self-sufficiency by providing transitional services (Foster Care Independence Act, 1999). The Foster Care Independence Act outlines state obligations and Governor accountability for adhering to various provisions of the CFCIP program which includes the development and implementation of a case plan with services for every foster youth transitioning out of foster care to ensure a seamless transition. Although Indiana enacted the CFCIP Medicaid Chafee option to extend Medicaid to former foster youth ages 18 to 21 in 2005, 8 of 9 participants were unaware of CFCIP entitling former foster youth Medicaid until age 21.

No renewal of current Medicaid before discharge. The Medicaid Chafee option coverage for Indiana outlines (a) youth who exit foster care at age 18 are eligible for Medicaid through age 21; (b) The youth’s case manager must submit a form to Medicaid indicating the youth’s continuing eligibility for Medicaid due to aging out of foster care; (c) The youth must sign an application to continue their connection to Medicaid; and (d) Youth who age out of foster care without maintaining their Medicaid eligibility may apply at the Department of Family Resources office in the county of their residence (Patel & Roherty, 2007). After further inquiry, a Family and Social Service Administration (FSSA) wardship Medicaid worker, employed by the Indiana urban county being examined, acknowledged “often times the referrals are not sent by the DCS worker” ([FSSA employee], personal communication, February 8, 2011). Eight of the 9 participants in this study did not receive continued Medicaid to which they were entitled beyond their 18th year. The experiences of the participants raise the question of whether or not the state is meeting its obligations, for the extended purposes of the CFCIP so as to ensure consistency of services, including Medicaid, for all former foster youth.

Limitations

There are intrinsic limitations of descriptive phenomenology as a research approach. Describing experiential qualities in the participant’s own terms is the basis of the research and the findings are not necessarily the “final ways or best ways” of articulating the phenomenon (Bloomberg & Volpe, 2008). Other limitations of the approach may include a self-selected sample, a desire to please the interviewer, and an ethnocentric bias (Chesnay & Anderson, 2008). The findings should also be viewed with caution because the research study was limited to one county in Indiana and cannot be generalized to other counties in the state or other regions of the United States.

Conclusion

The phenomenological approach describing the human experience of this research study provides rich experience descriptions by transitional uninsured former foster youth that can be used as a key source for knowledge and advocacy for foster care employees, social workers, health care providers and advocates of former foster youth. The capacity to create change develops through reflection and critical analysis of the status quo (Chinn & Kramer, 2007). With a better understanding of the experiences of uninsured former foster youth, sensible interventions can be initiated that address the foster youth’s reported needs.

The findings of this study can be used to inform legislators and influence health care policy legislation and policy implementation. The findings provide a basis for further examination of the structural deficit in policy implementation that systematically denied Medicaid to 8 of the 9 eligible former foster youth participants. For the Patient Protection and Affordable Care Act (PPACA, 2010) expansion in 2014 (Medicaid eligibility for former foster youth up to age 26) to be meaningful for former foster youth, the current challenges in enrolling in Medicaid (or continuing their enrollment) must be addressed. Former foster youth stakeholders need to make sure the best interests of foster youth are represented until the 2014 PPACA expansion of health care services. “Doctors, nurses, social workers and practitioners from diverse fields must engage at the state level and ensure health care implementation serves the best interests of vulnerable foster youth” (Hunter, 2011, p. 50).

Further investigation is also necessary to determine if the phenomenon observed in this study extend beyond the setting to other states and/or the nation. Further quantitative research that captures the incidence rate of foster youth exiting the foster care without their Medicaid insurance coverage is also warranted which would support a policy implementation change for the State’s Medicaid Chafee option, such as the renewal process used in Texas that automatically reenrolls discharged youth in Medicaid prior to discharge (Patel & Roherty, 2007).
According to U.S. Department of Health and Human Services Child Welfare Policy Manual, State legislation and policy changes may be necessary to comply with CFCIP requirements outlined in the Indiana Department of Children Services Independent Living Policy guidelines (Indiana Department of Child Services, 2010). Based on the study findings, suggestions for improved policy implementation are (a) ensure every foster youth aging out of foster care attend a mandatory briefing or presentation of all services available after discharge with full disclosure of eligibility; (b) accountability of juvenile judges to review transition plans on day of discharge and use a checklist to ensure that all requirements of the CFCIP program have been met including renewal of Medicaid (in states that elected the Chafee Medicaid extension option) prior to discharge (U.S. Department of Health and Human Services, 2011); and (c) systematic state and local quality assurance reviews ensuring the provisions of the Foster Care Independence Act and all State obligations to foster youth are being met with the Governor of State, ultimately accountable. As former foster youth Paul eloquently stated, “It’s just the right thing to do.”

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