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The Role of Parent Engagement in Overcoming Barriers to Care for Youth Returning Home after Incarceration

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Abstract

Purpose: To understand the role of parent engagement in overcoming barriers to care for youth re-entering the community following incarceration.

Methods: For this mixed methods study, we conducted quantitative surveys on healthcare needs and access with youth (n= 50) at 1-month post-incarceration, and semi-structured interviews with a subset of these youth (n= 27) and their parents (n= 34) at 1, 3, and 6-months post-incarceration (total 94 interviews). Differences by race/ethnicity and gender were assessed using chi-square test of proportions. We performed thematic analysis of interview transcripts to examine the role of parent engagement in influencing youths' access to healthcare during reentry.

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Implication and Contributions: Findings underscore the vital role of parents in promoting youths' healthcare linkages after incarceration. Approaches that leverage parent engagement, such as involving parents in pre-release healthcare planning, are promising.

Disclosures: The authors report no conflict of interests. The submitted work has not been previously published.

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Results: Most youth were from racial/ethnic minority groups and reported multiple ACEs. Girls, compared to boys, had higher ACE scores (p=0.03), lower family connectedness (p=0.03), and worse general health (p=0.02). Youth-identified barriers to care were often parent-dependent and included lack of: affordable care (22%), transportation (16%), and accompaniment to health visits (14%). Two major themes emerged from the qualitative interviews: 1) parents motivate youth to seek healthcare during reentry and 2) parents facilitate the process of youth seeking healthcare during reentry.

Conclusions: Parents are instrumental in linking youth to healthcare during reentry, dispelling prevailing myths that parents of incarcerated youth are inattentive and that youth do not want their help. Efforts that support and enhance parent engagement in access to care during reentry, such as by actively involving parents in pre-release healthcare planning, may create stronger linkages to care.

Keywords

incarceration; reentry; aftercare; parent engagement; access to care

INTRODUCTION

Racial/ethnic and socio-economic disparities within the justice system intersect with health disparities [1, 2]. Approximately 70% of incarcerated youth have at least one psychiatric disorder [3], and untreated mental health disorders increase incarceration risk [3]. In addition, more than 30% of incarcerated girls have ever been pregnant [4], far exceeding national estimates [5]. These health disparities suggest high unmet need for care among incarcerated youth, especially for reproductive and mental health care services. Although the law guarantees access to healthcare for incarcerated youth (i.e., youth adjudicated delinquent serving a sentence in a youth detention facility), linkage to recommended or mandated healthcare following release is not guaranteed and is generally poor [6–8].

Release from incarceration marks the beginning of *reentry*, defined here as the six-month period when youth transition to their home and community care settings [9]. Research has found that access to healthcare during reentry can improve youths' overall health, decrease recidivism, and improve educational and vocational outcomes [10, 11].

Parent engagement in adolescents' healthcare has been shown to improve outcomes for high-risk teens [12]. However, the role of parent or caregiver engagement in youths' access to care during reentry remains under-explored [13]. During reentry, youth often transition back to prior home, school, and neighborhood environments that may have contributed to their illegal behavior, while also having to meet court and probation requirements [9]. In this challenging context with multiple competing priorities, what roles do parents or other caregivers play in youths' accessing healthcare, and what roles are needed?

Qualitative studies have suggested that increasing parent engagement during reentry is an achievable goal that may decrease recidivism [14, 15]. These studies examined reentry broadly and were not specific to health or healthcare [14, 15]. Common barriers to care during youths' reentry include logistical challenges, such as lack of transportation and lack

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of insurance [6], youth disinterest in care [16], and structural barriers such as inconvenient appointment times [16]. To our knowledge, however, no prior studies have focused on delineating the role of parent engagement in youths' healthcare access during reentry. Further, studies on families' experiences in accessing healthcare longitudinally across reentry are lacking. To address these gaps, we examined the role of parent engagement in youths' access to healthcare across the six-month reentry period, from the perspectives of the youth and their parents.

METHOD

Design and Setting

Using mixed methods, community-partnered participatory research approach [17] for understanding healthcare access during reentry, we applied a convergent parallel design [18]. Quantitative data measured youths' healthcare needs, family factors, and the degree to which barriers to care were operating. Qualitative data was used to explain parental roles in influencing youths' access to care during reentry. Together, the study was conducted in partnership with a metropolitan juvenile justice system in the southwestern U.S. Community partners participated throughout all aspects of the study, including identifying the research question, developing the study protocol, and contributing to analysis and dissemination.

Participants

Youth returning home after incarceration within a juvenile detention facility in a large metropolitan county between November 2016 and March 2018 were potentially eligible to participate. Additional youth eligibility criteria included 12 years of age, fluent in English or Spanish, and no severe cognitive delay.

During the recruitment phase, youth exiting incarceration received a study flyer informing families about the study and inviting them to contact the study team. On a weekly basis, probation staff also provided the names and contact information of youth released during the prior week. The study team then telephoned each family on the list, inviting them for study participation. The confidential and voluntary nature of the study was emphasized as well as the study team's independence from the justice system. Informed assent and consent were obtained by telephone. Our university Institutional Review Board and the county juvenile court approved all study procedures.

Data Collection

Fifty youth completed the quantitative survey, administered at one-month post-incarceration. The response rate for survey participation was 44% (50/113), which is consistent with prior studies involving justice-involved youth in community settings [19]. A sub-set of youth survey participants and their primary caregivers also participated in longitudinal, open-ended interviews at one, three, and six months post-incarceration. We initially invited all youth who had completed the survey to participate in the open-ended interviews and then, to ensure a breadth of perspectives, purposively oversampled girls and fathers. Eleven youth survey participants declined to participate in an interview. Although our intent was to build a

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fully dyadic sample, 10 caregivers requested to participate despite their child not being available, most often due to re-incarceration or running away.

Surveys and interviews were collected in person or by phone, depending on participant preference. Youth and caregivers were interviewed separately, and responses were kept confidential. Surveys took an average of 30 minutes to complete. Results were recorded on paper by a research team member and then transferred to an electronic database (REDCap). Open-ended interviews took 30-60 minutes each and, with permission, were digitally recorded. Research team members trained in quantitative and qualitative data collection techniques conducted the surveys and interviews. When families had a language preference for Spanish, a native Spanish speaker collected the surveys and interviews. Participants were given a $30 gift card for each survey or interview completed.

Sample.

Derived from the sample of the 50 adolescents who completed the survey, the qualitative interview sample was comprised of 27 adolescents and 34 of their caregivers (94 interviews total). Caregivers included 28 mothers, 5 fathers, and 1 grandmother. For simplicity, we will henceforth use the term "parent" to refer to "parent/caregiver."

Survey instrument.

The survey instrument assessed adolescents' sociodemographic characteristics, family factors, health, and access to healthcare during reentry. *Adverse childhood experiences* (ACEs) were measured using a modified Center for Youth Wellness ACE Questionnaire-Teen self-report scale [20]. *Family connectedness* was measured via three questions, each rated on a five-point Likert scale (1= "not at all," 5= "very much"), that were summed to create a family connectedness score [21, 22]. *General health* was captured using a single-item response asking participants how they rated their health (excellent, good, fair, or poor) [23]. *Depressive symptoms* were measured using the eight-item Patient Health Questionnaire depression scale (PHQ-8), which asks about symptoms of depression in the prior two weeks [24]. *Perceived stress* was measured via the Perceived Stress Scale (PSS-10) to assess youths' self-appraisal of stressful situations in the prior month [25]. Healthcare access measures included single-item responses that asked about *health insurance status*, *barriers to care, and forgone care* since being home (i.e., not accessing care despite feeling it was needed); healthcare access measures were designed based on the Add Health survey [22].

Semi-Structured Interview Guide

The semi-structured youth and parent interviews explored youths' health needs and experiences accessing (or not accessing) healthcare during reentry. We assessed factors that influenced care access across medical, reproductive, and mental healthcare.

Analysis

Descriptive statistics were calculated to summarize quantitative survey data. Chi-squared tests of proportions compared ACE scores, family connectedness, and general health by gender and race/ethnicity. We performed inductive thematic analysis of the qualitative

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interviews [26]. First, audio interview files were professionally transcribed and then verified by our team. Second, using ATLAS.ti version 5.0 (ATLAS.ti GmbH, Berlin, Germany), three team members open coded youth and parent transcripts across the time-points. Interviews conducted in Spanish were coded in Spanish by native Spanish speakers. The team met several times to develop a preliminary codebook and code definitions. Once we reached agreement on the codebook, codes were applied to all the transcripts, after which we extrapolated codes to themes. During this process, a conceptual model depicting the relationships between the themes emerged. Convergence within and between parents and youth was examined and variation in barriers to care was explored across time-points [27]. We continued interviews until we reached saturation of major themes [28]. Finally, we considered the qualitative results in the context of the quantitative findings and triangulated interview findings with 20 interviews. Our team concurrently conducted interviews with juvenile justice and health professionals; thus, this analysis incorporated findings from 114 interviews.

RESULTS

Youth Characteristics and Care Access at One-Month Post-Incarceration

Youth and family characteristics are summarized in Table 1. The mean age of the youth participants was 17 years (range: 15-19). Thirty-six percent of participants were 18 or older, and 16% had completed high school or equivalent. Consistent with the southwestern juvenile justice population [29], most participants were male (88%) and most identified as Latino or African-American. The largest proportion of youth (38%) lived in single-mother homes.

Regarding ACEs, 69% of youth had parents who were separated or divorced and 56% had frequently experienced violence in their neighborhood or school (see Appendix A). Girls, compared to boys, had higher ACE scores (5 vs 2.6, respectively; p=0.03). Youth demonstrated relatively high levels of family connectedness (Figure 1). Girls, compared to boys, had lower family connectedness scores (6.2 vs 9.2, respectively; p=0.03). There were no differences by race/ethnicity for ACE or family connectedness scores.

Barriers to healthcare are summarized in Table 2. Youth had high self-reported scores on measures of general health. However, girls, compared to boys, had worse general health (p=0.02). General health did not differ by race/ethnicity. Most youth relied on Medicaid (46%) or did not have insurance (22%). At one-month post-incarceration, 18% reported forgone medical care and 16% reported forgoing needed reproductive care; notably, 20% of participants had either been pregnant or impregnated someone. Common barriers to healthcare included not prioritizing care (32%) and logistical issues such as lack of insurance (22%), not knowing where to go (22%), lack of transportation (16%), and lacking parental accompaniment (14%), all of which relate to parents.

Qualitative Findings

Two main themes about the role of parent engagement in influencing youths' healthcare access during reentry emerged: 1) parents motivate youth to seek healthcare during reentry, and 2) parents facilitate the process of youth seeking healthcare during reentry. Themes

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remained present across the six-month reentry period (Table 3). Over time, youth increasingly relied on parental support for linking them to care, while involvement by probation declined or ended.

Theme 1: Parents Motivate Youth to Seek Healthcare during Reentry

All parents conveyed concern about their children and described reentry as a high-risk period. Parents perceived continued access to healthcare as important, especially when part of a probation plan. Parents differed in the extent to which they felt responsible for motivating their children to seek care. All parents and youth articulated ways that parents motivate youth to access care during reentry. These mechanisms (i.e., sub-themes for Theme 1) are described below.

Parents care about youth.

Parents wanting their teen to seek care made their child feel cared for and thus motivated them to seek healthcare. Parents related a sense of caring and love towards their children; however, this did not always translate into their youth's perception of being cared for. Youth expressed that if they do not feel cared for by their parents, it dissuades them from caring enough about themselves to seek care, thus posing a barrier to accessing services. Youth and parents also noted that a parent's role in helping their youth access healthcare is unique because a probation officer could not love a child the way a parent does.

Parents convey value of care.

Youth explained that parents who themselves do not value care, or who are not informed about the importance of seeking care, are less likely to motivate them to prioritize care. One youth expressed appreciation that his parents told him that failure to access care would lead to getting "locked up again." Both the value of seeking care, and the parent's act of reminding him to seek care, motivated him to do so.

Parents enforce rules around seeking healthcare.

Establishing and enforcing rules about healthcare contributed to an increased sense of "discipline" that motivated youth to seek and receive care. Parents described "forcing" youth to receive care, despite youth often having competing priorities. Enforcing rules around seeking care and expectations about care were identified by both parents and youth as important.

Parents foster youths' independence.

Youth transitioning into adulthood expressed a sense of personal responsibility that increased with age. Youth and parents agreed that the increasing independence, corresponding to being "treated like an adult," included health maintenance. Healthcare navigation, rather than willful abandonment of parental responsibilities, was viewed as a positive and desired skill to impart to youth while fostering independence.

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Theme 2: Parents facilitate the process of youth seeking healthcare during reentry

While parents valued accessing care, they varied in their level of frustration with the process. Some parents were furious about challenges in accessing care, as many described burdens with logistical changes, while less commonly, others perceived accessing care as easy. Youth and parents felt that parents provided practical and emotional support in facilitating youths' access to care during reentry. The ways that parents facilitate youths' access to healthcare during reentry (i.e., sub-themes for Theme 2) are summarized below.

Parents obtain health insurance.

Obtaining insurance coverage was viewed as the responsibility of the parent, as youth and parents explained that children would "be lost" without parents solving insurance issues. Connection to insurance included re-instating Medicaid (which is suspended upon detention), helping undocumented youth obtain emergency Medicaid, or obtaining private insurance. Almost exclusively, parents elaborated on the challenges of re-instating Medicaid, a process that involved phone calls to the department of social services, probation, and health clinics, as well as occasional in-person follow up. Parents and youth expressed that lack of health insurance impeded access to non-emergency care, including court-mandated mental health services and filling medication prescriptions that were provided upon release.

Parents schedule health appointments.

For younger adolescents, both youth and parents viewed parents as responsible for scheduling youths' healthcare appointments. Although both parents and youth agreed that younger adolescents "depend on" parents for scheduling, some youth, especially the older youth, stated that they made their appointments themselves. While the actual act of scheduling was not described as a barrier, families expressed significant barriers that preceded it, which included lack of knowledge of available resources or providers, language barriers, and difficulty obtaining health insurance.

Parents provide transportation to health visits.

Most youth and parents stated that parents play a crucial role in physically taking their children to appointments. A few youth arranged their own transportation by riding the bus on their own, biking, or getting rides from friends. Barriers to transportation included parents' lack of availability and having to travel a long distance to reach care, as well as youth confidentiality concerns when seeking reproductive health services.

Parents provide accompaniment to health visits.

Parent accompaniment was viewed by youth and parents as instrumental, both logistically and emotionally. Participants expressed that parents assist with logistical aspects when present at a health visit, such as addressing insurance or billing paperwork and communicating with providers. Additionally, by accompanying youth, parents convey a sense of emotional support, which motivates youth to seek care and makes them feel supported. As one youth stated, "You gotta have someone to support and be like, 'All right, I'll go with you too.'" However, even in instances when youth had access to transportation independent of their parents (e.g., bus, ride from a friend), youth and parents explained that a

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barrier exists if parents have inflexible work schedules. This was particularly salient for parents who were undocumented, as they described having jobs that were inflexible or unstable, making it more difficult to request time off for their child's doctor appointments.

Parents provide financial support for healthcare costs.

Parents and youth stated that financial support for health visits was important. Parents felt it was their responsibility to pay for healthcare. However, some parents, especially the single parents, said that high costs prevented their child from receiving care. In contrast, others said they would find a way to pay through installments or by changing insurance plans.

Conceptual Model

Across the themes, a conceptual model emerged describing the role of parent engagement in influencing youths' healthcare access during reentry, contextualized within the systems and societal factors facing families during reentry (Figure 2). The model shows that, as expressed by the families, parents act to provide emotional and practical support to promote youths' access to care during reentry. Parents' ability to perform these functions is influenced by their type of employment. Jobs that are flexible and provide good wages as well as insurance coverage promote youths' access to care. Simultaneously, families interact with the healthcare and juvenile justice systems. Healthcare systems that are navigable and that facilitate Medicaid reinstatement promote access. Juvenile justice systems provide treatment recommendations and probation officers facilitate youths' linkages to care during reentry. Finally, we extrapolate from the families' statements and, as expressed by the 20 health and juvenile justice experts, this dynamic operates within the context of poverty, racism, and systematic discrimination that many justice-involved families face.

DISCUSSION

Across both data sources, findings indicate that parents are considered essential for linking youth to care during reentry, consistent with prior studies [6, 13, 16]. Together, these findings dispel the notion that parents of adolescents involved in the justice system are inattentive or that the youth are unappreciative and do not want their parents' involvement in their health [30]. Most youth in this study felt connected to their families. In fact, comparing results to those in the Add Health sample, the youth undergoing reentry reported higher family connectedness than the general U.S. adolescent population [22].

The multiple barriers to healthcare during reentry create a systemic disadvantage that strains parents' ability to demonstrate the emotional and logistical support needed to promote linkages to healthcare. These barriers heighten the importance of the role of parents and underscore the precarious challenge that many families face during reentry. The lack of observed differences by race/ethnicity suggests that poverty may be a stronger factor in healthcare access challenges faced during reentry. Many of the parents had identified risks that intertwine with poverty (single moms, parental drug use, and parental incarceration), creating more obstacles that hindered their ability to link youth to care during reentry. Barriers to healthcare may be especially problematic for the two groups that emerged as most vulnerable--girls and youth or parents with undocumented status. To overcome these

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challenges, parents need to be better supported in guiding youth to healthcare. Building on the already existing strengths of family ties and parent concern identified in this study may be a promising approach.

For older adolescents, youth and parents expressed a progression towards independence in healthcare navigation. Understanding the unique needs of transition-age youth during the high stakes period of reentry—a time when the next offense will lead to jail or imprisonment in the adult criminal justice system—is a worthy research focus [31].

Leveraging Parent Engagement

Reentry planning prior to a youth's release is a well-established, recommended practice [9]. While incarcerated, promoting parents' active involvement in reentry planning may sustain the benefits of care provided by the multidisciplinary team. Pre-release planning involving youth, parents/caregivers, probation officers, and health providers can communicate youths' health needs and follow-up care plan, and provide families guidance on how to navigate the system following release. Probation officers can view parents as allies in the process of linking youth to care.

Findings also suggest that health system solutions are urgently needed to improve access to healthcare during reentry. Youth and parent voices indicate a need for Medicaid policy reform to avoid gaps in Medicaid coverage during reentry [8]. Additionally, practical programmatic changes, such as releasing youth with a medication supply and transferring correctional health records to continuity providers, can ease family burden. Connecting youth to needed behavioral health and reproductive care services during reentry, in particular, has the potential to help shift youths' trajectories [10, 11]. Parents play a vital role in linking youth to care and in sustaining connections, especially once the support of probation has ceased. Nevertheless, in many instances, parents need more help than the system currently provides.

Limitations

Selection bias and differential loss to follow-up were a concern, as youth with closer family ties were more likely to participate and remain in the study. Youth returning to group home placements were not included. Given the stigma associated with justice involvement and with mental health, social desirability bias may also have influenced study results. Additionally, lack of trust may have limited the accuracy of our findings. Having the opportunity to follow families longitudinally and cultivate trust over time may have mitigated this to some extent.

CONCLUSION

Overall, findings from this mixed methods study consistently underscore the importance of parent engagement in influencing youths' healthcare access during reentry. Simply put, parents want to help, and youth want to receive that help. Leveraging existing parent engagement in overcoming emotional and logistical barriers to healthcare during reentry signifies a promising opportunity to heal youth—fostering a sense of being cared for, an

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opportunity to develop life skills, and access to medical benefits that can promote healthy trajectories.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations:

ACE	adverse childhood experience

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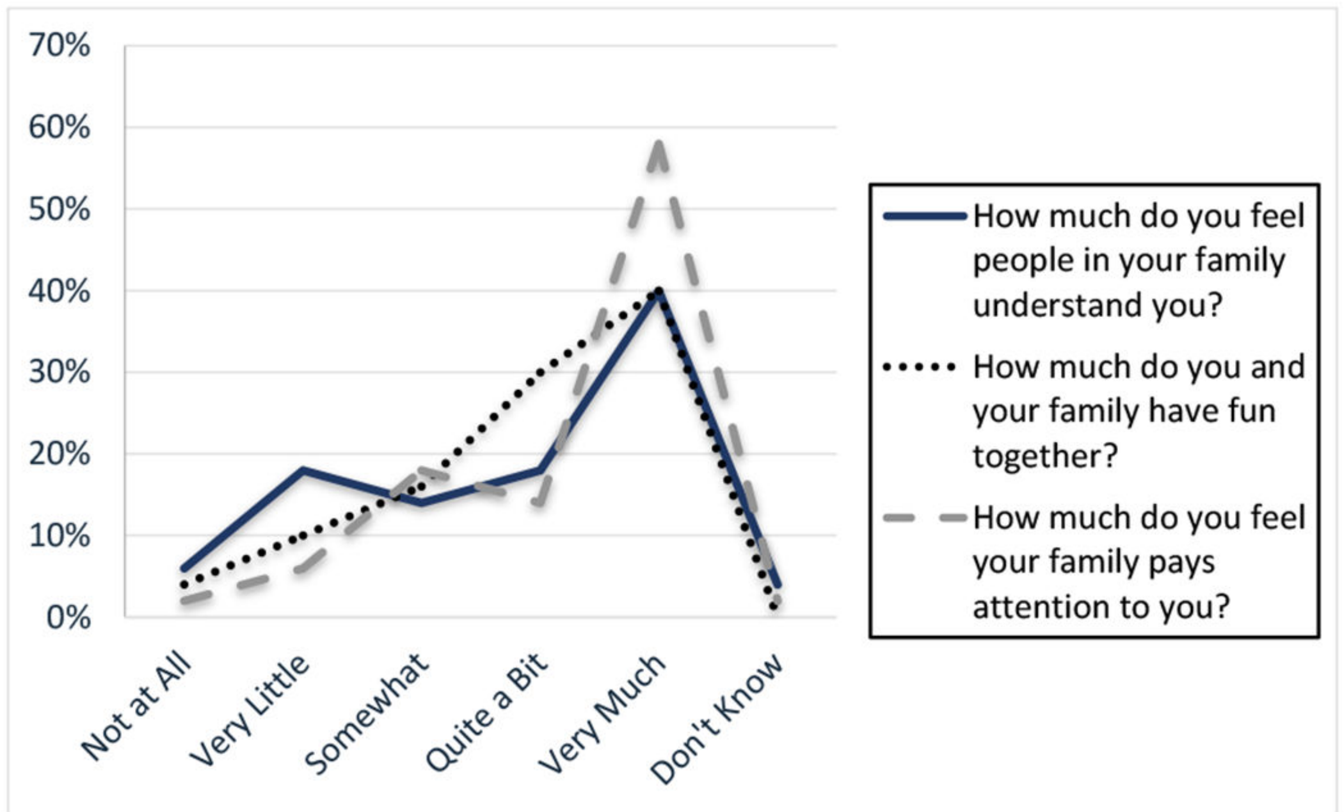

Figure 1.

Family Connectedness as Reported by Youth at One-Month after Release from Incarceration (N=50)

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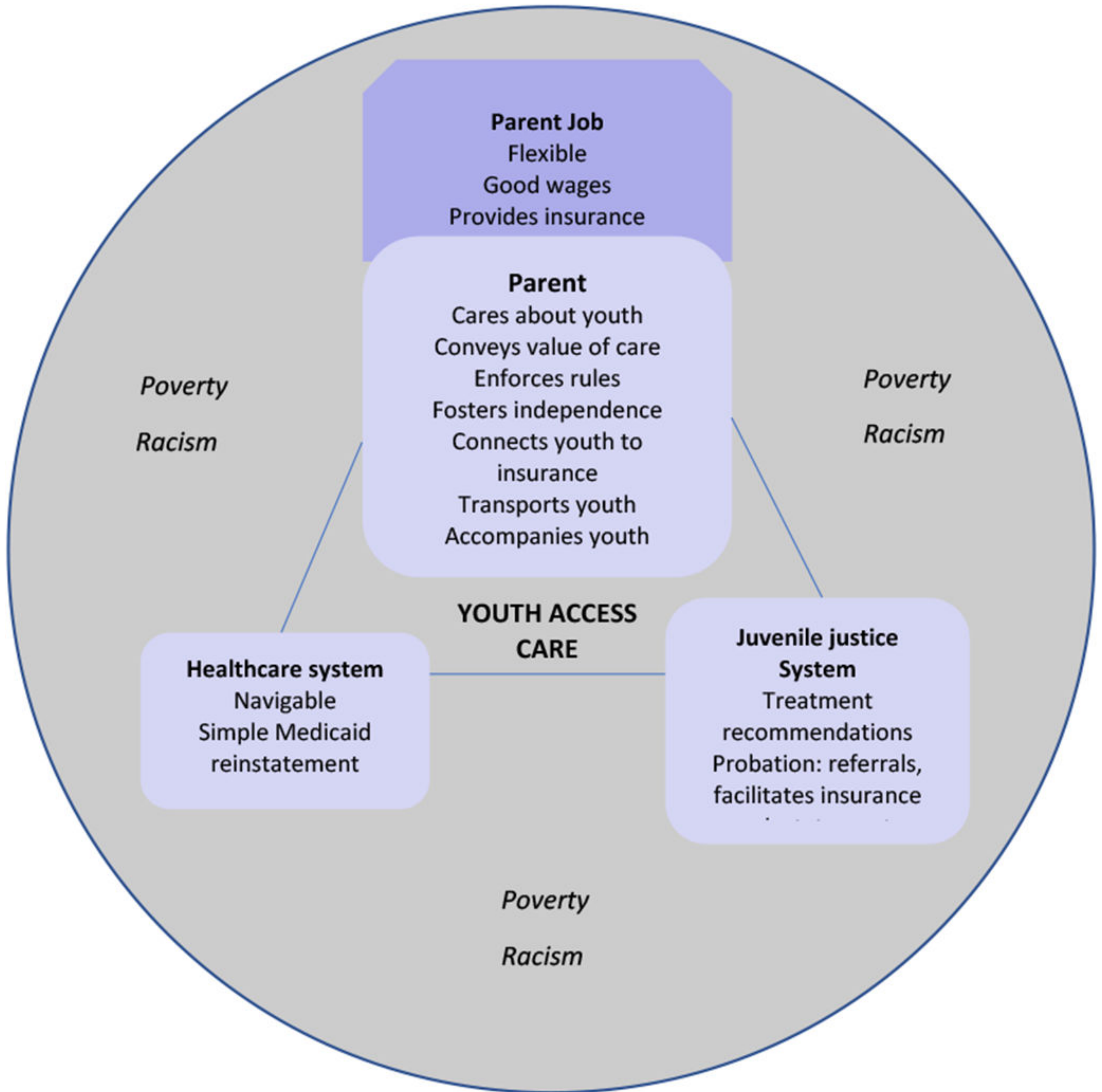

Figure 2.
Conceptual Model: Parent Engagement in Influencing Youths' Access to Healthcare during Youth Reentry

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Table 1.

Youth and Family Characteristics, Measured via Youth Surveys at One-Month after Release from Incarceration

Characteristics	**Number (%) of Participants (N= 50 participants)**	
Age (in years)		
15	4	(8)
16	9	(18)
17	18	(36)
18	18	(36)
19	1	(2)
Male	44	(88)
Race/ethnicity		
White	0	(0)
African-American	11	(22)
Latino/a	38	(76)
Native American	1	(2)
Asian/Pacific Islander	0	(0)
Education		
8th grade or less	1	(2)
9th grade	4	(8)
10th grade	15	(30)
11th grade	22	(44)
12th grade (high school graduate or equivalent)	8	(16)
Number of times detained/incarcerated		
Once	11	(22)
2-3 times	19	(38)
4 or more times	20	(40)
Household structure		
Biological mother and biological father	12	(24)
Two parents (at least one biological parent)	14	(28)
Single mother	19	(38)
Single father	2	(4)
Other	3	(6)
Home language		
Only English	21	(42)
English more than my other language	8	(16)
Both equally	14	(28)
My other language more than English	5	(10)
Only my other language (Spanish)	2	(4)

Characteristics	**Number (%) of Participants (N= 50 participants)**	
Adverse childhood experiences [*]		
Parents or guardians were separated or divorced	34	(69)
Often seen or heard violence in neighborhood or school	28	(56)
Lived with household member who served time in jail/prison	19	(39)

[*] Most common Adverse Childhood Experiences (ACE) exposures are reported in Table 1; 49 of 50 participants responded to these items. Appendix A reports full responses on ACE scale.

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Table 2.

Youth Health and Healthcare Access Measures at One-Month after Release from Incarceration

Item	**Number (%) of Participants (N= 50 participants)**	
Insurance		
Medicaid	23	(46)
No insurance	11	(22)
Don't know	10	(20)
Private insurance	6	(12)
Recommended while incarcerated to see doctor post-release	19	(38)
Felt the need for medical care in the past month but did not go	9	(18)
Felt the need for services related to screening or care for sexually transmitted infections, family planning, or pregnancy, but did not go	8	(16)
Barrier to seeing health professional		
Did not prioritize care or thought problem would go away	16	(32)
Couldn't pay or lack of health insurance	11	(22)
Didn't know where to go or how to make appointment	11	(22)
Had no transportation	8	(16)
No one available to go along or parent would not go	7	(14)
Didn't want parents to know	4	(8)
Afraid of what the doctor would say or do	2	(4)
General health		
Excellent	12	(24)
Very good	19	(38)
Good	12	(28)
Fair	5	(10)
Poor	0	(0)
Ever been pregnant or gotten someone pregnant	10	(20)

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Table 3.

Themes and Exemplary Quotes on the Role of Parent Engagement in Influencing Youths' Access to Healthcare during Reentry

THEME 1: Parents Motivate Youth to Seek Healthcare during Reentry
❖ *Parents care about youth* "I think [youth] need someone that really cares about them. Their parents, for them to tell them, 'Hey you've got to go'… Honestly, if I had nobody that cared about me, I wouldn't care about it." (18-year-old male)
❖ *Parents convey value of care* "As I tell my daughter, 'You are healthy, but you have to go every year to have a physical, to have blood drawn, because you never know, so many diseases develop that sometimes do not show signs so it is better to be aware, on time'." (Mother of 18-year-old female)
❖ *Parents enforce rules around seeking healthcare* "I'm not the health freak type person, but I do believe in taking care of yourself, because tha's how I was brought up. That is important to me, and I try to push that on him." (Father of 16-year-old male)
❖ *Parents foster youths' independence* "You have got to tell the kid, 'All right, you call this number. This is your next appointment.' Treat them like an adult so they know that, okay, I'm responsible for myself if something goes wrong." (17-year-old female)
THEME 2: Parents Facilitate the Process of Youth Seeking Healthcare during Reentry
❖ *Parents obtain health insurance* "I've never seen a kid at the doctor's appointment without a mom or a dad. I'm pretty sure most kids don't know what insurance they've got… They would just be lost." (17-year-old female)
❖ *Parents schedule health appointments* "Make appointments, take them to the appointments, and make sure that they're taken care of." (Mother of 17-year-old female)
❖ *Parents provide transportation to health visits* "Parents can take their kids to the doctor. Give them transportation." (17-year-old male)
❖ *Parents provide accompaniment to health visits* "There always needs to be someone, an adult to accompany [youth]." (Father of 15-year-old male)
❖ *Parents provide financial support for healthcare costs* "Sometimes people have to pay for prescriptions, or pay a co-pay, and would rather pay the money for something else, like maybe food for the house, or something… It's $25 every time I go to the doctor." (Mother of 18-year-old male)