

Patient Navigation through the Justice System: A Response to the High Infant Mortality Rate in One Community

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Abstract

The purpose of this evaluative study was two-fold; one was to evaluate a grant supported program that used the justice system to offer patient navigation services and the second goal was to provide a qualitative evaluation of the women's health care experiences as they went through a court mandated drug program. Primary data was obtained from interviews with forty-seven program participants (n=47) from March, 2008 until January, 2010, and participant observation was used to explore treatment modalities and options available to these women. Secondary data was obtained from program staff as well as a review of the survey evaluation process by the staff where data was collected through participant surveys. The findings suggest that poor outcomes for the women and their children are related to socioeconomic and/or behavioral barriers that produce difficulties forging successful relationships with traditional health care providers. When interventions that promote advocacy and empowerment are in place, there seems to be an improvement in outcomes for the mothers and their children.

Keywords

Social Capital, Social Cohesion, Empowerment, Infant Mortality, Drug Court

There is a growing body of evidence that building social capital is necessary for social and community cohesion and that infant mortality rates seem to improve in regions that are characterized by high levels of social capital (Kawachi and Kennedy 1997; Cook et al. 1999). We know from Durkheim's theory of the individual and society that social integration is necessary in order to build social networks and have full participation in society (Durkheim 1951; Israel 1985). Studies have shown, however, that efforts at social integration for the court involved population often fail and recidivism rates seem to be correlated to the length of time that participants spend in the program

as well as the type of program, i.e. longer treatment programs have a better chance of success (Prendergast et al. 2006). According to Speer, Jackson, and Peterson (1990), what might be necessary for health promotion is building social capital and increasing social cohesion through empowerment.

Empowerment is a concept that has been linked to social cohesion in numerous studies (Collins 1990; Sampson, Morenoff, and Gannon-Rowley 1998; Braithwaite 2004). Speer, et al. (2001) found that, social cohesion is related to intrapersonal empowerment with empowerment being 'an intentional ongoing process centered in the local community, involving mutual respect, critical reflection, caring, and group participation, through which people lacking an equal share of valued resources gain greater access to and control over those resources' (2001:716). Public health research demonstrates that social capital is linked to morbidity and life expectancy. Additionally, health status is influenced by income inequality and participation in society or the lack of social cohesion (Cook et al. 1999; Kawachi and Kennedy 1997; Turner 2004). Turner (1993) discusses this idea of social capital, citizenship, cohesion, and democratic participation within the context of vulnerability and human rights. He states, 'A sociology of rights attends to the social and economic foundations of rights, in which the protection of human vulnerability is the key component of human rights' (1993:112). According to Verschaegen (2006), Turner is one of the few sociologists to devote attention to the study of human rights and he does so by 'grounding human rights upon human embodiment and the shared vulnerability of humanity' (2006:217). Women and children have historically been categorized as vulnerable populations and their health status has been linked to poverty, disease, warfare, and globalization (Travis and Compton 2001; Farmer 2004; Turner 2006). Turner argues that, 'Sociology can ground the analysis of human rights in a concept of human frailty, especially the vulnerability of the body, in the idea of the precariousness of social institutions, and in a theory of moral sympathy' (2006:490). This study then, considers the work of Speer (1990) and Turner (2004) in order to evaluate a patient navigation program whose stated goal was to decrease the infant mortality rate for a group of court involved women by building social capital through an advocacy based empowerment approach.

Despite the efforts of multiple agencies in Hillsboro (pseudonym for city under study which is located in the northeastern part of the United States) infant mortality remains a significant problem. Statistics show an infant mortality rate of 9.5 for this city; a rate that far exceeds the Healthy People 2010 (a statement of national health objectives by the Office of Disease Prevention and the United States Department of Health and Human Services) goal of 4.5 for infant mortality. For the years 2006-2008 in Hillsboro, 10.2% of births were low birth weight, and the pre-term birth rate was 12.1% of all live births (for reference purposes the New York State average is 11.7%). In addition, the pre-term birth rate is generally higher than the community averages among women who report use of alcohol and/or illegal drugs (Zuckerman 1989; Goldenberg 2000; Bada et al. 2005).

Infant mortality and poor childhood health rates have long been considered indicators of the socioeconomic disparities on the health of populations; a social barometer that highlights poverty, lack of education, lack of affordable housing, and access to health care (Gortmaker and Wise 1997). Wise and Pursley (1992) state that infant mortality rates are a kind of 'social mirror' that reflect broad inequalities in society and illuminate the social injustice of communities. Some scholars have found that poor childhood health, as evidenced by a low birth weight, is a factor in numerous negative outcomes, even to the extent of reproducing generational inequality and the availability of life chances (Case, Fertig, and Paxson 2005; Haas 2006).

A major contributing factor to these poor outcomes of pregnancy is poor socioeconomic and/or behavioral circumstances affecting health care access in Hillsboro. Studies show that neighborhood characteristics have been proposed to influence birth outcomes and health disparities through psychosocial and behavioral pathways, yet empirical evidence is lacking (Schempf, Strobino, and O'Campo 2008). Other studies have shown that there are structural barriers to prenatal care for at-risk populations that include scheduling conflicts, costs of care, and transportation difficulties (Tossounian, Schoendorf, and Kiely 1997; Cook et al. 1999; Mikhail 2000; Daniels, Noe, and Mayberry 2006). Most of these experts believe that community factors need to be addressed to measure this type of stress as it relates to health disparities.

The court-involved population often mirrors these socioeconomic and behavioral circumstances for poor outcomes. For example, a 2003 report on New York State drug courts noted that 33.4% of Hillsboro's drug court clients were homeless and only 33% had a high school diploma or GED; only 25% of the court's clients were employed or in school¹. The rates of recidivism, incarceration, non-compliance and court ordered dissolution of families (usually single parent) appear to be strongly linked to the presence or absence of family housing and basic support services, including health care.

Hillsboro has a drug court that was established in January of 1997 and has operated successfully since then as part of a nation-wide effort to integrate criminal justice system processing and substance abuse treatment. The first drug court in the United States was started in 1989 in Miami-Dade County, Florida as a response to the crack-cocaine epidemic, 'they found a solution by combining drug treatment with the structure and authority of the judge'². Today, there are over 2,559 drug courts all over the United States with the purpose of reducing criminal involvement and promoting abstinence among drug using criminal offenders (Online Report 2011). The drug court is intended to improve the outcomes for drug dependent offenders, reduce criminality, improve the allocation of scarce criminal justice resources and promote public safety. Ancillary services are an essential part of the drug court and are incorporated into the drug program based on the recognition that the effective treatment and relapse prevention must address all areas of life functioning (Resource Guide and Handbook 2001). Research shows that no other justice intervention has been as effective as that of drug courts (Roman, Townsend, and Bhati 2003; Fox and Huddleston 2003). Drug courts blend numerous systems and their outcomes have proven to be successful and cost effective (Huddleston, Douglas, and Casebolt 2008).

The cost savings for drug courts are impressive, with cost savings ranging from nearly \$3,000 to over \$12,000 per client, and those who graduate from drug courts have lower recidivism rates than offenders who do not go through a drug court program (Roman et al. 2003; Aos et al. 2006). This research also shows that because of the integration of numerous systems, graduates of drug court are able to interact more effectively with the community when they have access

to health care, educational/job training, and treatment modalities.

According to those working within the drug court system, what seemed to be lacking for Hillsboro was the health care component. Many of the women enrolled in drug court told the staff that they had difficulties finding physicians to treat them as well as problems obtaining health care for their children. Pregnancies were especially complicated to manage due to women who were giving birth while taking suboxone or methadone. Suboxone, in particular was problematic because it is under studied in terms of use during pregnancy, clinical trials are ongoing for neonatal dependency withdrawal and the use is under reported (clinicaltrials.gov 2009; NCT00521248; McNicholas 2008). It seemed to those who were working within the drug court that they noticed a relapse during the post-partum period that made it difficult for the women to maintain program compliance.

DESCRIPTION OF THE PROGRAM

Driven by concern over the high infant mortality rate, a social worker in Hillsboro wrote and was awarded a grant from a national non-profit organization in order to set up a project that was specific for the group of women who were going through drug court. Before the program's inception, these women had little involvement with formal health care services, health statistics for this group were missing, and the case workers were finding that many women in this group did not have prenatal care or postpartum care. In addition, they were having difficulty finding pediatric healthcare for their children. The program that was developed was titled, 'Patient Education and Navigation for High-Risk Women.' This work builds upon research done by Olds et al (1986) that showed evidence for the effectiveness of nurse home visiting during pregnancy for improved birth outcomes among disadvantaged women. According to the program description, the concept of individualized nursing care is implemented as an intervention in the form of patient navigation; individualized to meet the needs of every client (Jensen 2006).

Much of the discussion and public debate about infant mortality has focused on prevention and improved access to prenatal care (Gortmaker and Wise 1997; Loveland-Cook et al 1999; Schempf et al. 2008). Hillsboro followed this national trend and the focus for

reducing infant mortality was on prevention and treatment programs for prenatal care with the majority of funds going to the local safety net hospital and the county health department. The rate, however, remained alarmingly high with very little evidence of improvement over the past decade. The program that was developed by the social worker, however, took a different approach. The program was built from the 'ground up' and was placed near the courtroom in order for the women to services when they attended their court-mandated appearances.

The patient navigation office is located in the Judge's chambers; the judge for the drug court offered to give up his chambers so that the nurse and social worker would have an office that was physically close to the drug court. The office is located through the door that the Judge and staff use to enter the courtroom. The office is a small room without windows, and just enough space for two chairs that face a desk and chair. There is a small row of shelves against one wall that holds donated items and health brochures. The donated items include formula, diapers, personal toiletries (mostly samples that people have brought in from hotels), toothbrushes and toothpaste. Every corner of the office has boxes stacked on top of each other that contain donated clothes (staff and Judge have all donated items). The Judge's robes are hanging on the back of the door.

Because the office is physically located in the drug court (Judge's Chambers) it makes access to the women much easier. It also allows for more communication and collaboration between the medical community and the justice system, with the goal of improved health care delivery. Many of the women do not want visiting nurses or social workers to visit them in their homes. Additionally, because of the demands of drug court, it is sometimes difficult for these women to be home during the day for visiting nurses or social workers.

The providers (nurse and social worker) went to where the women were and addressed the concerns for this specific group. According to the providers, the program offers assistance with the procurement of a medical home for all those clients who are pregnant and/or parenting a child less than 1 year of age and who do not currently have a medical home. The rationale for the program design

is to build upon the existing infrastructure, with the intent to expand services and client population, as well as to formally offer health education and referral services.

During the court session, the nurse and social worker sit to the side of the courtroom in chairs reserved for staff and attorneys. There is a lot of activity during the court session with people entering and leaving in an almost constant stream. Additionally, the staff is often not seated long because many of their clients will need to have interview sessions with the counselors and drug court staff; court dates are often dual-purpose events. As the women enter the courtroom, the nurse and social worker identify those who are pregnant or parenting a child and will then get up and ask the women if they can meet with them before or after they go before the Judge. If the women agree to meeting with the nurse and social worker, then they are escorted to the office. All of the women agreed to this meeting during the course of the study. Twice during the course of this study the nurse also handed out items and information to men who had pregnant girlfriends.

The program is voluntary and the potential participants are referred to the program case manager to discuss case management and patient navigation services. During initial screening, program staff will explain the program, give pre-tests; provide information about folic acid use and preconception and interconception care, discuss participants' status with medical providers, and give post-tests and referrals. Approximately one hour is spent with each client during each visit; however, program staff often spend more time with women who are pregnant or parenting a newborn. Following initial screening, the case manager begins the process of finding a medical home and offers to accompany program participants to their medical appointments. The program also provides parenting education, and program staff will assist with other postnatal care issues, including procurement of a medical home and patient navigation/medical case management.

The drug court personnel and family court personnel are supportive of the project, and all involved rely on ancillary services in seeking successful outcomes for their clients. Consequently, the program is multidimensional since referrals are received from both the drug court and the family treatment court (participants involvement in

the program does not affect their standing in court). Female clients who are pregnant and at risk for a poor birth outcome such as preterm birth, and/or low birth weight due to the negative social, economic, cultural, safety and health factors associated with prostitution and/or substance abuse are identified in the initial meeting with the nurse educator (patient navigator) and encouraged to actively participate in the program. The staff will then facilitate the procurement of a medical home for all those clients who fit the criteria. In addition, if the woman chooses, the nurse educator/patient navigator will accompany pregnant participants to their prenatal and post-partum visits. The nurse educator offers support to clients during these appointments, and also reinforces medical recommendations between appointments. By encouraging and supporting pregnant drug court and FIC women as they attend their prenatal appointments, the program has the rationale of decreasing the chances of experiencing a negative birth outcome such as a major birth defect, and/or delivering a low birth weight/preterm infant. Through education, instruction, and advocacy the staff will seek to empower the female clients with knowledge and provide them with a tool (Preconception/Interconception Health document or PIC), which will serve as a mechanism to more thorough communication with their medical providers. The staff also provides Folic Acid specific information and free samples of multivitamins with Folic Acid in order to decrease the risk of having a child with a major birth defect.

The main goal of the program is to decrease the infant mortality rate in Hillsboro with patient navigation as the pathway, and the secondary goals are to increase the awareness of Sudden Infant Death/Safe Sleep, Lead Poisoning Prevention, and Shaken Infant Syndrome to all clients who are pregnant or parenting an infant by providing education, support and referrals. The program's five main objectives are: 1) increased folic acid-specific knowledge by program participants; 2) increased use of folic acid supplements by program participants; 3) increased procurement of medical homes (a single medical facility where all of a patients' records are kept) for pregnant/parenting program participants; 4) increased knowledge and use of preconception/interconception care (spacing pregnancies for the mother's health and to encourage better parenting) by program participants; and 5) increased procurement of medical homes for the

children of program participants.

EVALUATION OF THE PROGRAM AND SERVICE DELIVERY/IMPLEMENTATION

The primary goal of this study was to evaluate the patient navigation program and to provide information in order to create a sustainable model of health care through the justice system. The secondary goal was to explore the health care experiences of this group of women and examine how they manage to obtain health care within a system that is often difficult and unaccommodating to their needs. Another consideration for this project was to examine the concept of socialization and resocialization as identified by the criminal justice system. In order to obtain qualitative information for this study, a symbolic interactionist approach was used to gain an understanding of the experience of health care for this population and to evaluate the program from the participant's perspective.

As of February 2010, the staff had met with over 268 women. Twenty-six women had given birth, and 24 of these births were full-term (24 out of 26). The two births that were premature were over 32 weeks with hospital stays for the infants of less than three weeks. The project nurse educator/patient navigator acted as a labor coach at two of the deliveries and assisted with specific information, navigated office visits and guidance with 25 pregnant participants as of December 2009. The staff also made many referrals to various services including: medical providers, Healthy Start the County Health Department (CHD), for lead screening, CHD for Social Work/Mental Health Screening Service, Planned Parenthood, Family Planning, Dental Services, the Spinal Clinic, a smoking cessation program for African-American Smokers, the NY State SMOKERS' QUITLINE, and The Safe Sleep program.

METHODS

This study used a combination of field observations and interviews. IRB protocol was followed and IRB approval was obtained in March, 2008 with an extension obtained in March, 2009 through March, 2010. Because the participants were court-involved, the IRB protocol stated that I could not ask any questions regarding their criminal activity. My questions were to be specific to their

experiences with the patient navigation program and health seeking behavior.

Access to the sample population occurred through participants' word of mouth as well as an announcement through the program. A total of 47 women (n=47) were interviewed and these women did meet the study criteria (pregnant and/or parenting a child under the age of 5). Many of the women initially contacted me and requested an interview, not knowing the specific study criteria. Because this study considered the infant mortality rate in Hillsboro, it was necessary to find women who had given birth within the past five years, been pregnant within the past five years, or were parenting a child under the age of five.

Between 2/01/08 and 2/01/10 there were 192 women enrolled in the drug court program. Approximately 32% of these women were identified as African-American, 48% were Caucasian, 3% were Native American, 4% were Hispanic, and 4% were identified as other race/ethnicities, with the remaining percentage not identified with any race. The women selected for the study reflect the demographic data for drug court enrollment; with the exception of Native American. There were no Native Americans interviewed for this study.

The majority of women going through drug court in Hillsboro identify as Caucasian. This fact seems to be common in many areas of the country and research has addressed this problematic area (Dannerback et al. 2006; Wolf 2009). Robert Russell, a former chairman of the board of the National Association of Drug Court Professionals, states, 'some drug courts' eligibility criteria have the unintended effect of excluding minorities. A rule excluding all but first-time offenders, for example, might render a disproportionate number of black or Hispanic offenders ineligible.' (Wolf 2009:44) Gebelein, a drug court policy expert says, 'In identifying target populations, drug courts need to be sensitive to class and race bias. Unless care is taken, diversion courts may tend disproportionately to work with white and middle-class substance abusers' (200:5). According to some scholars, African American women are often unfairly targeted based upon crack use during pregnancy (Roberts 1997; Washington 2006). Roberts states: 'When Newsweek charged that 'drug addiction among pregnant

women is driving up the U.S. infant mortality rate,' 'it blamed Black mothers for a trend that predated the crack epidemic. Black mothers are thus made the scapegoats for the causes of the Black community's ill health' (1997:179). A study is currently taken place in Hillsboro to investigate whether some of these nation-wide trends are responsible for the race distribution in drug court.

Between 2/01/08 and 2/01/10 there were 190 (only two declined) women enrolled in the program who received an individualized educational session, 25 pregnant or parenting women who received individual education sessions, and 25 pregnant or parenting women who received individual medical case management/patient navigation services each project year. Because the numbers for each group are low (approximately 25) it is recommended that qualitative research will play a significant role in determining the success of the individual programs.

Forty-seven in-depth tape-recorded face-to-face interviews (n=47) were conducted in order to record the experiences of the women who were enrolled in the program. Semi-structured interviewing using audio taping with verbatim transcription was the primary method for obtaining data and the interviews took place in a location chosen by the respondent (e.g., respondent's home, local coffee shop, library). All interviews were conducted informally to allow for unanticipated topics that might arise during the interview. The participants were all from Hillsboro and had varying income and educational levels, although the majority was receiving some form of public assistance (42 out of 47).

Observational data were collected in order to supplement interview data and to assist with describing the daily experiences of the women who participated in the study. Participant observation took place from April 2008 to April 2009. Observations were conducted inside the drug court proceedings, several health care clinics, private physician offices, and a neonatal intensive care unit. These locations were chosen because they were places where these women go to receive healthcare or ask healthcare related questions. The observations at these particular locations addressed the research question of how these women manage their healthcare. The investigator obtained consent for the participant observation before the observation occurred and the investigator was introduced as a

researcher and the purpose of the research explained to the participants. The researcher was identified as a mandated reporter and this information was listed on the consent form (Vallandra 2007). The consent form was offered and consent was received from anyone that the investigator had an extended conversation with during or after the participant observation.

The specific research questions for this study were: 1) Does individualized navigation impact the rate of preterm births? 2) Does patient navigation impact the rate of low birth rates? 3) Does patient navigation assist with program compliance? 4) Does patient navigation assist with socialization and subsequent success?

Research questions were divided into three categories:

- 1) Access
- 2) Development and Design of Non-Profit Institutions
- 3) Available Services

I did not ask questions related to their criminal charges. The charges were irrelevant to this evaluation. I only talked about family history as it related to health history and this was accomplished through open-ended questions with information voluntarily offered by the participant. In other words, probing questions were not asked in regard to history. In addition, questions regarding charges or past activities might have had a negative impact on the study because it would not promote trust between the researcher and the participant. This study very specifically deals with access issues and the development of a nonprofit organization based on consumer needs and demands. By finding out what works for these women, we will be able to design a nonprofit organization that directly addresses their wants, needs, and desires.

After the first several interviews and observations, it was evident that there were common themes noted by the women and the quotes found in this paper were selected as examples of these responses. Glaser and Straus (1967) state, ‘...in discovering theory, one generates conceptual categories or their properties from evidence; then the evidence from which the category emerged is used to

illustrate the concept' (1967:23). Overwhelmingly, the women spoke freely and were eager to have their stories told as evidenced by an average interview of 2.5 hours. It was not uncommon to have to end the interview after three hours due to the time constraints of the respondents.

Qualitative information is necessary in order to design a sustainable model for these women if the model is to be designed from the ground up; however, there are some limitations for this type of research. Trust and power imbalance are the two most significant areas to address. All but two of the women interviewed stated that they 'did not trust other women' (see discussion of this in findings) and they really did not like 'the nurses from the agencies' (identified as county health department and university affiliated hospital). I am female, my early background is in nursing (intensive care and public health for seventeen years) and I have a doctoral degree in social science from a major university -- that means that I am part of 'the system' that these women do not trust. Twine and Warren (2000) in 'Racing Research, Researching Race' offer a quote by Wittgenstein, 'If a lion could talk, we could not understand him' (2000:251). The authors continue on this theme, but state that they would like to add the words 'at first' to the end of the phrase (2000:251). They believe that over time the two would find meaning to their communication and that it cannot be taken for granted that there would be automatic problems of communication (Twine and Warren 2000). Indeed, many of the women seemed to view me as being separate from the institutions that they found troubling and most stated that they were thrilled to have their voices recognized - especially when the topic of housing arose. Most of the women interviewed thanked me for interviewing them and many said that they would like to be represented if a model program was developed.

FINDINGS

Study participants enter the drug court program with multiple problems, and these women generally have few sustaining relationships with little evidence of socialization. Many participants spoke casually of traumatic experiences with common themes of oppression, abuse, and a history of foster care. Additionally, the majority of participants were challenged by financial situations that

were exacerbated by limited education. Other themes that emerged were problems finding adequate child care, trust, transportation, difficulty managing medical care and public benefits, and most were unable to find safe, stable housing. Overall, however, participants appeared resilient despite having faced many challenging and traumatic events.

During the course of this study, there were no infant deaths and no children died during the first year of life for any of the women who were in the study group. There were twenty-four full term births and two births that were greater than 32 weeks with both babies having hospital stays of less than three weeks. According to the women interviewed, the navigators for the program were involved in some aspect of prenatal care for all of the pregnant participants.

Detailed information from the findings illustrated that all but one of the participants had a history of child welfare involvement either during their own youth or as a parent of a child going through child protective services. Thirty-eight of the 47 participants had spent time in the foster care system during their youth, and all of the participants had been separated from at least one of their children at some point during the child's life. Overwhelmingly, participants stated that they wanted to be better parents. Over half (32) of the participants had one or more children in foster care and/or with a court appointed relative, and one or more children living with them. They referred to this as the 'kids I lost' and the 'kids I want to keep'. This meant that these women had a set of children who were in foster care and had been removed from their home and then a second set that were currently with them as they went through drug court. It was the aim of these women to keep their 'second set' with them as they went through the mandated programs, with the hope of maintaining an intact family. Keeping the family intact was how they described being 'better parents.' One participant who fit this description said, 'I don't want to mess up and lose these kids. They are all I have. I lost my first kids and now one of them is in jail. I can't have that happen again' (OP, age 36).

Trust was a common theme that arose during the interviews. All but two of the women stated that they did not 'trust other women.' (The two women who did not state this were both white, suburban females, ages 22 and 39). The majority of women who did

not trust other females said that they 'hate their mothers' and that they did not have any other women whom they would call their friend. Most of the women did not have anyone in their life that they could depend upon to assist them with activities of daily living or court requirements. Many people in our society are suffering from social isolation (see McPherson, Smith-Lovin, and Brashears 2006), but for these women there are severe consequences. Not being able to make a court appearance or a doctor appointment because of travel problems, child care, or work related problems might mean sanctions that could include prison time or health complications. Compounding this issue are some of the effects of the Rockefeller Drug Laws which have affected relationships, especially for women of color (Correctional Association Report 1999). According to Tinto (2001), qualitative studies have shown that many of the drug crimes committed by women are affected by (and maybe even a result of) an intimate relationship with someone who buys or sells drugs. There did seem to be an exception in terms of female relationships for all of the women involved in the study. When they were asked if they trusted Joanne (navigation nurse), all of the respondents stated that they did trust her and that they relied on her like they would a family member. Questions regarding the mother/daughter relationship are beyond the scope of this study, but the topic of female trust sheds light on some of the problems associated with group living.

There is little doubt that housing had a positive impact on the participants, but securing permanent housing was difficult for most of the participants. Proper housing appeared to be related to compliance with many of the program requirements. Currently, when entering a half-way house (often only option available), the women must comply with a required plan of 30 days in-patient treatment; their children, then, must enter foster care. Participants who were eligible for program housing during treatment found that it positively affected other areas of their life, such as reducing stress and the ability to remain compliant with the requirements of the program. Participants also stated that being able to keep their children with them made it much easier to remain compliant. The participants who did have their children with them stated that having a 'room for each child' was the most important aspect of permanent housing and they saw this as their goal for long term housing options. They felt that by providing a

better environment for their children, this allowed them to provide 'the experience of childhood' that many said they had not experienced in their own lives or with their first set of children.

The area that brought common responses and complaints by most of the women was that of health care (for each woman, as well as their experiences as parents for their children). All of the women interviewed used the term 'half step' to describe the care of services they received from health care providers. They overwhelmingly stated that they felt the 'system' short changed them or 'half-stepped' them and that they did not receive the same benefits or services that 'regular paying people' receive. They also stated that they did not 'trust the system' and they did not want 'those nurses from the health agencies' in their homes. This is especially interesting in terms of the navigation program because they did not feel that Joanne (pseudonym for nurse navigator) was part of 'the system.'

All pregnant participants interviewed stated that Joanne was able to get them into 'regular' health care and away from the 'poor people's clinic.' This reference was to the free health clinic that represented the main source of health care delivery for this group of women prior to intervention by the nurse navigator. Participants who were not pregnant also stated that their primary source of health care prior to intervention by the nurse navigator was the free health clinic. The majority of participants stated that their health history included giving birth to at least one child without receiving any prenatal care at all (44 out of 47). Participants related that they would not have been able to manage their health care without the assistance of the nurse navigator program. All pregnant participants interviewed, who used the nurse navigator, stated that they felt Joanne was able to 'talk to the doctor' for them and 'get me the help I need'.

One woman stated that she tried to go to a 'regular' doctor by herself, but she encountered too many problems:

I tried to go to the private guy for my hepatitis. They told me that there is only one guy in town who takes care of that kind of thing and so I went, but he was just too rude and down right mean. He wouldn't listen to me and he was only in the room for about five minutes. He didn't even examine

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me. I went back for my next appointment, but they told me that I was late and would have to reschedule. I was only a couple of minutes past my appointment. And I mean I had to take the baby to the day care and two buses to get there. Forget it. Too much hassle. I don't need to go to that much work just to be treated bad.' (AR, female, age 26)

All of the women interviewed who used the nurse navigator stated that this practice assisted them with services that they would not have been able to access or would not have known about without the assistance of the nurse. All of the women stated that they called the nurse at least one time on her work cell phone to either ask a question or ask her to accompany them to the doctor. Additionally, all of these women stated that the nurse was able to get services for either their children or their own care that they would not have been able to obtain without her assistance. One woman said:

Yeah, Joanne (pseudonym for nurse) did more for me than anyone else has ever done. She was great. She was there for every doctor appointment and even during the delivery. I called her at night once and she met me at the hospital. I couldn't have done it without her (DS, age 21).

Only one woman interviewed was able to obtain private insurance for her children on her own. This woman indicated that she found out about the program and then she was able to obtain assistance from a local charity where staff members assisted her with filling out the forms and sending in the application. She heard about the opportunity through word of mouth and then told several of her friends who were also in the process of filling out the forms (the name of the charity and the name of the insurance program are being withheld in order to protect the identity of the respondent). Two other women interviewed for this study were in the process of obtaining this insurance for their families. All of these women were African American.

This same woman also took her children to a private pediatrician at a for-profit hospital and she never used any of the free clinic services for herself or her children. None of the women interviewed currently used the safety net hospital or the safety net hospital clinics for any of their care. When they needed to find a physician, they either used the free health clinic or the emergency rooms in the for-profit hospitals located in Hillsboro. Childbirth deliveries took place at these for-profit hospitals. One woman, in particular was adamant about not using the safety net hospital:

I wouldn't go there and I wouldn't take any of my kids there. They treat you like you are poor and stupid. One time, a nurse yelled to another person in the emergency room that I was a welfare case. It isn't like that at City (Name changed). They don't really seem to care what kind of insurance I have (JL, age 29).

Transportation was a challenge for participants as it interfered with their ability to maintain compliance with their many court scheduled activities and treatment programs. Additionally, the bus service and routes sometimes forced them into compromising positions as they came into contact with people from their past. Few (2 out of 47) owned their own vehicle and public transportation was difficult to navigate due to bus schedules and the lack of a cross-town bus in this particular city. Hillsboro has two direct bus routes, but both are connected to the institutions of higher education and both are subsidized through a government grant and/or funds from the college and university. One of the direct bus routes goes from the university to a satellite university facility and the other direct route goes from the liberal arts college to the local mall. According to the transportation officials, primarily students from the local university and college use both of these bus routes. These officials also stated that the government subsidized routes were part of a safety plan that was designed for students due to increased violence and thefts on the city bus routes. None of the women interviewed had ever taken the direct routes nor had they heard of the term used for the route that goes from the university to the satellite facility. Even though the

subsidized routes are direct and have lowered fares, the women were not aware of this service nor could they have benefitted from this transportation route because they did not live in the university area.

One participant, who had given birth six weeks prior to the interview stated:

It is really hard to take a newborn on the bus, you know. I mean I have to change buses twice and carry all her stuff to the day care. Then, I have to go to treatment and do that all over again at the end of the day. Sometimes, it takes me two hours of travel in one day and I only go about ten miles. I don't like the people on the bus either. Sometimes there are men on there who bother me and harass me. I don't need that kind of attention right now. I am trying to get better, you know (JH, age 21).

Because of the requirements and opportunities available through drug court, many of the women interviewed were involved in a job training/skills program, had plans for part-time employment/volunteer activities after graduation from drug court, or were in an educational program. Eighteen (out of 47) women were in a vocational training program within the health care industry (nurse assistant, diploma nursing program, operating room scrub technicians, ultrasound technicians), or had plans to go into this area upon graduation from drug court; the remaining participants were involved in vocational training, working on their GED, or community college course work with the exception of six women who were on some form of disability insurance.

The requirements for drug court took a great deal of the women's time and many stated that they had difficulty making time for anything else. One area that consistently seemed to be neglected was well child visits for their children. Additionally, the importance of these visits was not articulated during the interviews. One woman said, 'I don't see a reason to take him to the doctor. He ain't sick' (FE, female, age 22). Four of the women interviewed stated that the nurse navigator had assisted them with finding pediatricians and health care

products and supplies for their infants. All of the women with children had used the navigation office for supplies at least one time during their court appearances. The women who had given birth during their court mandated time seemed to recognize the value in pediatric care.

One participant stated:

With my other kids, I didn't have nobody to help me or tell me things. They (nurse and social worker) know what it is like. And they don't make us run all over. We just tell them what we need and they have it or they find it for next time. Yeah....they made my life a lot easier (NM, age 32).

TARGET POPULATION/EVALUATION

Strengths

1. Participation in Drug Court
2. Resilience
3. Support Staff
4. Desire to change behavior in order to provide a better life for themselves and their children

Challenges

1. Navigating Medical Care within a medical model
2. Poverty
3. Child Welfare and/or Threat of Foster Care Involvement
4. Housing
5. Transportation
6. Navigating Medical Care for Children

EVALUATION AND FINDINGS OF PROGRAM OBJECTIVES

For evaluation purposes, data was collected by program staff (nurse and social worker) via simple true/false, low-literacy pre- and post-tests about the use of multivitamins with folic acid, and knowledge and use of information provided about preconception and interconception. With the help of participant surveys, the program staff collected data on the program's success in securing medical

homes for patients and their minor children.

During the program's first year, clients scored an average of 2.1 (out of a possible 5 points) on the folic acid pre-test and an average of 4.4 (out of a possible 5 points) on the folic acid post-test. Overall, 75% of participants scored higher on the post-test. On the preconception and interconception (PIC) test, clients scored an average of 2.5 (out of a possible 5 points) on the pre-test and 3.6 on the post-test. Overall, 58% of program participants scored higher on the PIC post-test. In addition, 89.6% of the program participants reported that they had established a medical home, and all program participants who reported having infant children, stated that they had established medical homes for their children (Jensen 2010).

This was a grant funded program through a national non-profit with an award of sixty thousand dollars a year for a total of three year, funding of seven hundred dollars from the Kiwanis club for incentives, and approximately three thousand dollars over a three year period for donated items. The salary for the social worker was twenty three thousand dollars a year and the salary for the nurse was fifteen thousand dollars a year with forty percent in fringe benefits for the employees (indirect costs and office supplies). (Total cost for program was \$61,233/year).

For a cost/benefit discussion it is important to consider the cost of a premature infant. According to an article by Russell et al. (2007): Costs per infant hospitalization were highest for extremely preterm infants, although the larger number of moderately preterm/low birth weight infants contributed more to the overall costs. Preterm/low birth weight infants in the United States account for half of infant hospitalization costs and one quarter of pediatric costs, suggesting that major infant and pediatric cost savings could be realized by preventing preterm birth (doi:10.1542/peds.2006-2386).

Recent facts regarding the cost of prematurity also state that the cost of a preterm infant is approximately ten times greater than the medical costs of full-term infants with the average cost ranging from \$51,600 to greater than \$65,000 depending on the region. According to an Institute of Medicine report, in 2005, preterm births cost the United States approximately \$26.2 billion or \$51,600 for every infant born prematurely³. Direct costs may be stated in the comparison of a premature child with that of a full term infant.

The topic of foster care and the costs associated with foster care are also important to include in the cost/benefit analysis because of the number of children in foster care for the identified population. A recent report by O'Hare (2008) states, 'comparisons based on Census Bureau data show that households with foster children are different from other households with children on almost every dimension examined.' The report goes on to say that in general, households with foster children are disadvantaged compared to all households with children. In terms of living arrangements, the analysis for the report shows that compared to all households with children, households with foster children are typically larger than other households with children, less likely to be married couple households, more likely to have an adult householder who did not work in the previous year, more likely to report receiving public assistance income, less likely to have a householder who graduated from college, and more likely to be low-income as measured by an income of less than 200 percent of the poverty line (O'Hare 2008). Additionally, foster children have higher rates of incarceration, poverty, homelessness, and suicide. The recent research shows that foster care placements are more detrimental to children than remaining in a troubled home (Lawrence, Carlson, and Egeland 2006).

DISCUSSION

According to Malterud (1993), 'Decisions about health care delivery have usually been in the domain of professionals and health officials. Although professional groups have been dedicated to the quality of health care, women's voices have been noticeably absent from health service and evaluation' (1993:370). There is no question that oppression can be viewed as one of the most disempowering forces for these women, and the literature demonstrates that issues of women's reproductive health are linked directly to inequality and oppression (Collins 1990; Gortmaker and Wise 1997; Cook, et al. 1999; Cramer et. al 2007). Kawachi and Kennedy (1997), as well as many social scientists, have stated that ever since Durkheim's 1897 study of Suicide (1951), the foundations were laid for theories of social capital and the subsequent health consequences.

Building social capital in this group of women is imperative for positive outcomes and successful socialization. The women in this

study have stated that building relationships is necessary in order for them to maintain compliance with the drug program. So it would seem that the major source of empowerment for them was through micro level measures rather than macro level measures. For instance, they were able to complete their requirements for the program with the aid of a navigator. It was not enough to have the institutional support; what they needed was assistance in maneuvering a system that was sometimes unaccommodating to their needs. To accomplish this, a social identity (Mova and Hames-Garcia 2000) needs to be developed that would create a new group with collective behavior; thereby, assisting these women with their daily demands. Mova and Hames-Garcia (2000) discuss the common experience of discrimination, coercion, and domination that creates a social psychology for members of these groups that influences worldview, norms, and self-expectations. Breaking this negative cycle might be possible through navigation as well as the creation of a micro-foundation/kinship model for housing.

Because employment is linked to social cohesion and socialization, it is also important to consider employment and the importance of work on health outcomes and resocialization. Aizer, Llerbas-Muney, and Adrianna (2008) found that maternal underemployment is linked to low birth weight for pregnancy outcomes and in individual levels of subjective distress for the mother. Boardman, Padilla, and Hummer (2002) found that 'birth weight is significantly related to developmental outcomes, net of important social and economic controls and the effect associated with adverse birth outcomes is significantly more pronounced at very low birth weights' (2002:353).

Many of the women interviewed voiced their concerns regarding foster care. The most common theme was stated by one woman (JF, age 32), 'I don't think anyone else can take good care of my children like I can. No one loves my kids like I do.' Therefore, it is important to consider human costs and social capital costs for this group of people and for the communities where they live. These secondary costs are an important consideration for future outcomes. Building human capital and social capital so that families may remain intact, has a return of about ten percent or greater for communities, companies, and countries that employ methods of increasing human

capital according to social science research (Becker 1993; Zhan 2006).

The time horizon is different for this group of women and supports the concept of a time horizon that is differentiated by class (Lareau 2004). This group of women tends to think of the 'here and now' and this focus on the present hinders them from seeking preventive health care, especially prenatal care. Drug court staff stated that they felt the education offered by the navigation team assisted with compliance and an understanding of the importance of prophylactic health care during the prenatal period for future positive outcomes. Evidence to support this can be found in the outcome data from the pre and post testing done by project staff as well as the health status of the infants born to the women in the program.

This research presents the possibility that resocialization efforts often fail because basic socialization for this group has never occurred. More work needs to be done in this area in order to consider these factors of unequal distribution; taking a multidimensional approach to health care disparities in this town would provide opportunities for successful socialization. By taking a multidimensional approach to the health disparities and the related outcomes noted in this group of women, a housing facility could be developed that would promote the health care advocacy and socialization process. One-on-one mentoring, including accompaniment to office visits by staff would provide one avenue of advocacy that could be used as a teaching tool for improved outcomes, further empowerment, and obtaining social capital. The program's case managers could facilitate the empowerment process and assist clients to gain knowledge and strength in their abilities to eventually navigate through the healthcare system by themselves.

The family housing facility would provide an opportunity to keep families intact while providing additional opportunities for treatment options and education; helping these families achieve successful socialization. This facility would be based on a kinship model and would take an interdisciplinary approach to health disparities; providing unique partnerships with the justice system and collaborating community organization. Many of the women state that they feel 'like outsiders' and don't know how to make the 'system work.' Although the mother/daughter relationship was beyond the scope of this study it is important to consider this finding in terms of

the power control theory (Hagan 1988) when thinking about implications for the study. The power control theory predicts that parents' positions of authority in the home and at work will determine how 'gender roles are interpreted and reproduced by their children' (Hagen 1988:4). By initially building a social identity that is based on collective experiences (group home with children – kinship model) it would seem that this group of women would be able to maintain their unique personal identities, while learning to function in society and advocate for themselves and their children; thus building social capital and producing positive socialization. A move from periphery to center would not necessarily mean taking on the characteristics of domination that are often present for this group (the Center), but rather empowering them so that exploitation no longer occurs (Hooks 2000).

This, however, is only a partial aspect of the empowerment process because the process of holistic empowerment is incomplete if it is lacking cohesion. This is a useful concept because it focuses on the community as well as the individual; a critical element of holistic empowerment and successful socialization. Partnerships with local community groups to provide mentoring would be a useful tool that might assist with socialization. Basic living skills would be taught in a family type atmosphere that would benefit both parent and child.

A 2001 report from the National Institute of Health (NIH) to the Senate Committee on the Judiciary stated:

The most visible example of the blending of public health and public safety approaches can be seen by the growing number of drug courts that have been established over the years. More than 600 drug courts, which mandate and arrange for treatment, monitor progress, and arrange for other necessary services as needed, are currently operating across the country. NIDA is currently supporting research that is looking at the effectiveness of some of the different drug court approaches that are being utilized⁴.

Missing from this approach is the advocacy, socialization measures,

and empowerment that are needed in order for this group of women to obtain success with the program and to become productive members of their communities.

Findings from this evaluation show that building social capital through empowerment is imperative for positive outcomes and successful socialization. The program under study took a multi-dimensional approach to the problem of infant mortality. They formed a program based upon the needs of those who were experiencing the phenomenon or a 'ground-up' approach. By blending health care with the justice system, they were able to provide advocacy in a form that empowered the women going through drug court. In turn, the women were able to maintain compliance with the program and keep their families intact.

In addition, this evaluative study defined the health disparities for this group and the subsequent consequences. The disparities specific to this group of women are poverty, lack of adequate housing, lack of job training, lack of a medical home for women and their children, inability to navigate the often complicated health care system, lack of adequate nutrition, lack of transportation for court mandated responsibilities, lack of transportation for access to medical care, and day care for children. These disparities are often the result of the absence of adequate family housing and the associated social network. Bryan Turner (2004) has stated, 'Health, like income is unequally distributed through the population, but the distribution is not random. Age, ethnicity, gender, income, residence, and status significantly influence the incidence and distribution of health' (2004:5). Adding a family kinship model for housing would complete the program and help these women deal with one of the most troubling aspects of their recovery, which is proper housing in order to keep their families intact.

CONCLUSION

The evaluation findings suggest that infant mortality can be reduced with a patient navigation program for high risk populations. In addition, health care outcomes and program compliance were improved for this group of high risk patients. It appears that among the most disadvantaged and vulnerable members of society, providing individualized support services that empower the individual may

improve socialization and will increase compliance for program participants. This compliance may then be observed through improved outcomes for their dependents. This program was a unique and innovative agenda that used an encounter with the justice system as an opportunity to offer a healthcare intervention and build social capital.

It is important to reiterate that during the course of this study, there were no infant deaths and no children died during the first year of life for any of the women who were in the study group. There were twenty-four full term births and two births that were greater than 32 weeks with both babies having hospital stays of less than three weeks. This finding is especially significant when considering the infant mortality rate for this area, which has historically been greater than 9% for the past decade. This study suggests that poor outcomes are influenced by poor socioeconomic and/or behavioral circumstances, which result in women not forming effective connections with the health care system. Agendas that concentrate on funding institutions for interventions related to infant mortality may not be the answer for this vulnerable population because these programs are not reaching all of the at-risk women.

These institutional programs (often hospital based or county run visiting nurses) have also not proven to be as cost effective as the program under study and there has been no measurable difference in infant mortality despite numerous institutional attempts to reduce the rate in Hillsboro. Turner (1993) places institutional failure within the context of social precariousness and human rights. 'The basic idea here is that social institutions are in the long run often inadequate to human purposes' (1993:503). The women interviewed did not use the safety net hospital nor did they find the health department to be responsive to their needs. The organizations that were designed to assist these women were the same organizations that the women found very difficult to use. Turner states, 'There is the perennial argument in sociology that primarily as a consequence of bureaucratization, human institutions change over time in such a manner that they eventually deny or negate their original design' (1993:503). Turner also draws upon Weber's 'institutionalization of charisma' when he articulates 'the idea that over time institutions can no longer adapt to the conditions from which

they originally sprang' (1993:503). When interventions that promote advocacy and empowerment are in place, there seems to be an improvement in health outcomes. Using a human rights approach provides insight into what is necessary in order to build a model health care program for these women.

Research shows that comprehensive treatments that focus on the whole individual, and not just on drug use, have the highest success rates, especially in terms of health outcomes (Monchick, Scheyett, and Pfeifer 2006). These programs provide a combination of behavioral treatments, medications, and other services, such as referral to medical, psychological, and social services. The array of services provided must be tailored to the needs of the individual patient. In addition, previous studies tell us that drug addiction treatment programs that adhere to scientific principles benefit not only the patient and his immediate community, but the larger society as well (Hancock 1999; Gorman 2003; Heck et al. 2003). A health oriented, holistic approach would draw upon the field of health education which has historically concentrated on individual health behaviors rather than on building social capital and the consideration of social cohesion (Speer et al. 2001). Coupling this approach with empowerment seems to improve birth outcomes and builds social capital in order to create a sustainable model for housing and health.

Further research needs to be done in this area of women's reproductive health. The court involved population is at risk for many health care disparities with poor outcomes that will have a lasting impact for the women and their children. We need to gain a better understanding of the unique needs and experiences that face these women. By doing so, we may then apply the findings in order to create model programs that will give the women a voice and will move them towards empowerment, allowing them to advocate for themselves and their children.

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Endnotes

1. <http://www.ncsconline.org/wc/courttopics/ResourceGuide.asp?=&DrugCt>
2. <http://www.nadcp.org/learn/what-are-drug-courts/history>
3. <http://www.marchofdimes.com/prematurity/21198.asp>
4. <http://www.nida.nih.gov/Testimony/3-14-01Testimony.html>

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