Hepatitis C and the Social Hierarchy: How Stigma Is Built in Rural Communities

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Abstract
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Keywords
Qualitative Research, Rural Community, Hepatitis C, Stigma

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Hepatitis C and the Social Hierarchy: How Stigma Is Built in Rural Communities

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Although Hepatitis C has profound impacts on individuals living in communities, most research has been conducted in a hospital or laboratory setting. Additionally, there is a lack of research exploring the social effects of Hepatitis C in rural communities. In this qualitative study, we focus on perceptions on Hepatitis C within a rural community, describe how the local residents perceive social hierarchy within their community, and explore the process of stigma building. Informed by a grounded theory approach, we employed a snowball sampling strategy in a southern rural area to conduct in-depth, open-ended interviews. In our findings we describe how local restaurants were often utilized as places to exchange personal opinions on various community issues among the upper hierarchical members, consider the ways social hierarchy influences people’s perceptions, and explore community members’ response to the problem of ignored viral infections within the community. We found the community leaders are earning the trust by living in the community for an extended period of time; therefore, they tend to be elderly yet remain active as members of various committees. Additionally, we argue that the common view of “family-like support” in rural communities is largely a myth; it is a romanticized view of the rural living held and perpetuated by the upper-class people in the community. Therefore, instead of depending on idealized or imaginary social support, rural communities need to consider organizing a system of formal support. Keywords: Qualitative Research, Rural Community, Hepatitis C, Stigma

Introduction

The contraction of Hepatitis C is largely linked to socially perceived deviant behaviors such as intravenous drug use and homosexual activities (Centers for Disease Control [CDC], 2016). Authors of many research studies have described the various causes of infection with the Hepatitis C virus, its effect on the patient’s health, and how to manage living with Hepatitis C (e.g., American Liver Foundation [ALF], 2015; CDC, 2015, 2016; Holmberg, Spradling, Moorman, & Denniston, 2013; Mintz, 1992; Nash, Bentley, & Hirschfield, 2009). When compared to the research conducted on the viruses themselves, there is a lack of research on the mechanism of how members of society develop this negative perception of Hepatitis C. This lack of information on the social repercussions due to the illness may add to the further negative stigma attached to the illness. In addition, the majority of research tends to focus only on the patients in urban communities or in a hospital setting (e.g., CDC, 2016; Conrad, Schneider, & Gusfield, 1992; Holmberg et al., 2013; Zacks et al., 2006). Therefore, there is a need to study the process of stigma building from the views of members in a rural community and to explore how family members of the patients are viewed in the community. To gain a
better understanding of how these perspectives are developed, we explore the aspects that contribute to the development of social stigma of Hepatitis C in a rural community.

We begin with a review of previous studies followed by our research methods and findings. In our concluding discussion section, we consider what type of social support system is needed for viral infections carriers and their families in a rural community.

**Literature Review**

**Hepatitis C**

The Hepatitis C Virus (HCV) is a contagious, blood-borne infection which causes the liver to become highly inflamed (CDC, 2015, 2016). Although Hepatitis C begins as an acute virus, it can stay in the body and become a chronic infection (CDC, 2016). Typically, if a person is infected with acute HCV, there is a 75-85% likelihood that chronic HCV will develop. In 2013, an estimated 3.5 million individuals had chronic HCV compared to 29,718 cases of acute HCV (CDC, 2016). Interestingly, those infected with HCV do not show any symptoms for a long time. Symptoms typically begin to show after a person has been infected with chronic HCV and the liver has begun to sustain damage (CDC, 2016). Symptoms include tiredness, muscle achiness, joint pain, fever, low to no appetite, nausea and vomiting, itchiness of the skin, stomach pain and bloating, dark urine, clay colored feces, and jaundice (ALF, 2015; CDC, 2016). Because a person does not show symptoms until there is already damage to the liver, identifying the initial contraction can be difficult.

Recently, HCV is gaining attention because of its longer dormant period. The dormant period can be up to 30 years, which means many Baby Boomers, defined as those born roughly between the 1940’s and 1960’s, are just now beginning to show symptoms. According to the CDC (2016), the Baby Boomer generation is most at risk for carrying HCV because of unsanitary medical procedures conducted before 1987—more so than illegal drug use. Current research is focused on the contraction, transmission, and treatment in this generation. However, there has not been a sufficient amount of research focusing on the relationship between social interaction in rural communities and the development of stigma towards HCV. In addition, more understanding is needed regarding why and how individuals are stigmatizing this particular virus.

**The Effect of Age on the Perception of Hepatitis**

As described above, there is the possibility of contraction through medical procedures and other procedures, such as tattooing, blood transfusions, and dental surgeries, which happened prior to the late 1980s, before health and medical professionals became more aware of the risk. This, in particular, impacts the Baby Boomer generation (Conrad, Garrett, Cooksley, Dunne, & McDonald, 2006; Holmberg et al., 2013). Although the high-risk Baby Boomer generation represents a significant proportion of the population, research by Zacks et al. (2006) suggests that social rejection, internalized shame, and financial insecurity are common experiences among HCV patients regardless of age group or other factors like socioeconomic status. This finding is important because although this generation was highly susceptible to contraction due to improper health procedures, reactions towards patients are often based on stigmatized ideas of transmission such as drug usage or sexual promiscuity.
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The Image of Deviance and Stigma on Hepatitis C

Within the symbolic interactionist approach, views of morality are determined by the actors, culture, time, and setting in society. In reality, what are described as socially acceptable morals are the byproduct of the upper social hierarchical community members’ beliefs (Conrad, Schneider, & Gusfield, 1992). Thus, deviance is any action that is not within the standards of these powerful groups’ beliefs (Conrad et al., 1992). These moral beliefs continue through socialization and interactions among the community members.

These same moral beliefs might affect the development of social stigma in relation to Hepatitis C. In some cases, the social stigma affects the patient, family, and friends associated with the virus. Because there is an association of drug use and the contraction of HCV from drug use, many individuals believe that Hepatitis C is deserved. This belief helps contribute to the withdrawal of treatments, prevention of diagnosis, and contributes to the self and social isolation of Hepatitis C patients (Marinho & Barreira, 2013).

Since influence and beliefs are typically created from the upper class of communities, there is a need to investigate the group of the upper-class people and their behavioral and thinking patterns to help understand the entire community. In addition, there is a lack of information about the relationship between the level of overall education and the stigma held for Hepatitis C among residents in rural communities. Contrary to the general understanding of how the upper-class values education, we suggest that this generalization does not necessarily hold true for the upper class in some rural communities, especially in respect to public health education.

Length of Residence and Perspectives

Average length of residence of the community members is another important aspect that might influence stigma about HCV. When the level of partisanship and average years of residence within the community are high, this potentially encourages continuation of long held attitudes including social stigma of HCV. As a result, there is resistance to changing attitudes, so community acceptance of our newly diagnosed or infected community members is less likely, regardless of the original of the infection. Without this sense of social connection, a person infected with HCV may feel excluded from work, school, church, or other social settings. The CDC (2016) has emphasized the detrimental impact of social isolation and accompanying lack of social support on health outcomes.

Purpose of this Study

In this study, we hope to discover the factors that contribute to the building of social stigma of Hepatitis C in rural communities. By analyzing the backgrounds of individuals in a rural community, we hope to improve our understanding of factors influencing the perceptions of diseases which are considered the result of deviance. For the purpose of this study, we understood deviance as any activities that may cause harm to one’s health or social reputation, which the upper hierarchal group finds unacceptable. In order to close the gap between the previous knowledge and uncovered areas, we will consider factors that we believe might encourage certain perspectives about Hepatitis C such as age, level of education, length of residence, and knowledge about HCV. In addition, the relationship between one’s perception on HCV and his/her social status, income, race, and ethnicity will be examined.
Role of Researcher

The first author initially explored this subject matter as a part of her academic training in one of her undergraduate courses. After her acquaintance told her a story about the struggles of social isolation related to viral infections in the rural community, she further developed this research direction and conducted the pilot study reported here. The second author was initially the first authors’ academic advisor and supervised and collaborated with the first author on this current study.

Methods

Selecting Qualitative Inquiry

One of the focuses of our study is to understand the processes of stigmatization based on Hepatitis C in a rural community. It was our hope to uncover the common themes that members of rural community found from their experience in terms of Hepatitis C. Since the holistic and rich nature of qualitative data enables us to reveal the complexity of the study subject in a real contextual setting (Miles & Huberman, 1994), we recognized an inductive approach would be the best way to discover the common themes of rural community members’ perceptions on Hepatitis C in a complex society.

Grounded Theory Approach

Grounded theory lets researchers convey a conceptual map of the phenomenon while offering openings for study participants to express their opinions to contemplate the issues, which result in gaining new comprehensions (Glaser, 1998). This would be complemental to the ultimate goal of our study since we hope to suggest enhancing rural communities’ support system, and this requires including the local people’s views and understanding on the issues.

Consent Process

In accordance with the Institutional Review Board (IRB) in the institution where we both belonged to at the time of data collection, each study participant gave written consent before answering any questions, and they received a copy of the consent form. Since the majority of the population with Hepatitis C is middle-aged or above 30 years and are established in the workforce, this allowed us to observe their place on the social hierarchy in the community. For this reason, we purposefully excluded minors from our study. Participation in this study was voluntary and the participants received no monetary compensation. They were instructed to contact the researchers if they had questions or concerns about this study. Additionally, participants were reminded that they were allowed to stop the interview and withdraw at any moment and did not have to answer any questions that made them feel uncomfortable. The risks in conducting this study were minimal, and included potential discomfort experienced while talking about health issues. During the interviews we conducted for this research report, we received no serious reactions or reports of anxiety or severe discomfort experienced by the participants during or after the interviews.

Location

Since the majority of the attention has been given to the perspectives of urban communities on Hepatitis C in previous studies, this study took place in Riverside, a
pseudonymous rural community in one of the southern states in the United States, away from any big cities. The population of Riverside was an estimated 4,500 and the median household income is approximately $24,000. The main businesses of the community consisted of a couple of chain restaurants; however, most other businesses were locally owned. White residents comprise the majority race/ethnicity (85%); other represented populations include Hispanic/Latino, African American, Native American, Asian, and others, along with those who identify with two or more races. The median age of the Riverside residents is 40.3 years old. The study participants were residents of this community; they may or may not have knowingly interacted with people with Hepatitis C or may or may not have had any knowledge about the disease. This condition was important to this study since one of our research interests was how stigmatization based on a certain illness was developed and how it was diffused to people who have no knowledge of the illness.

**Recruitment and Data Collection**

We used a snowball sampling method by starting with personal acquaintances, and we asked consenting participants to refer potential participants who might be interested in talking to us. We chose this method because we knew we were going to collect data in a small, close-knit community for a limited time period. Due to the low population of Riverside, we believed snowball sampling would be more effective to collect interviews. Without the original connection, we may not have been as welcomed into the community, which would have prevented potential referrals. Since we used open-ended questions, we strongly encouraged the participants to express their opinions and thoughts freely, and within our semi-structured interview guide, we allowed the conversation to take its own direction and allowed participants to expand the topics—especially when participants were fervent about expressing certain opinions. All face-to-face interviews were audiotaped, transcribed within a week after the interview, and stored electronically in password-protected computers. The shortest interview took approximately 15 minutes and the longest interview was approximately 2.5 hours; the average interview time was about 30 minutes. Some participants felt more comfortable answering the questions in written form.

We stopped recruitment when our analysis revealed no additional new themes and concepts from the participants. All study participants answered the questions in a face-to-face interview format, but they had the option of performing a written survey. We asked the participants’ perceptions on topics such as their understanding of Hepatitis C, how the patients and their family members are treated in the community, and how they think about their own community related to the issues of Hepatitis C. We also gathered demographic information from participants including their gender, age, length of residency in the community, current occupation, and income. However, in order to protect their privacy and ensure the confidentiality of their participation, we used pseudonyms for all individuals’ names and places mentioned.

**Data Analysis and Quality Control**

Qualitative methods are not only to offer a new input in some topics or situations within different subjects or another facet of the same focus, but also to refine existing theory or to form additional theory which leads to theoretical innovations (Lofland, Snow, Anderson, & Lofland, 2006). Our tasks were to uncover and to conceptualize the process of stigmatization through the perceptions of the residents on Hepatitis C in a rural community.

The second author purposely did not get involved with the data collection process in order to enhance credibility and trustworthiness of the findings. By taking these steps, the
second author was able to read the transcribed data objectively to check any possible biases by asking critical questions to the first author and to comment on any information that presented itself as subjective. For example, the second author asked the first author to reflect on how she was feeling at the time of interviews in addition to asking participants’ facial expressions, body language, and tone of voice. Then, we spent a considerable amount of time contrasting and comparing the phrases to make sure there was no bias affecting the processes of data analysis and drafting results.

Using grounded theory analysis methods, we began with open coding and through this process identified some interrelated themes including stigma, community diversity, social hierarchies, and viral infections. Next, we moved on to axial coding and further developed themes based on common terminology such as poor people, leaders, upper-class, and Hepatitis C.

Certain themes became more prevalent such as processes of stigmatization, indifferent attitude toward HCV carriers due to lack of education about Hepatitis C, disregarding the welfare problems, and blindness to drug problems or an unwillingness to fix the problems. After gathering common themes, we utilized the selective coding approach; our intention was to see how the rural community’s characteristics affect the residents’ perceptions on HCV and how the residents apply the perceptions to determine other people’s status as well as their own in the community. Through selective coding, we also supported our claims by identifying relevant, direct quotes from the participants.

Findings

Participants

We collected a total of 30 interviews with personal narratives, life histories, and opinions on the topics of illnesses in the Riverside community from May 2016 to August 2016. Seven males and 23 females—27 identified as White and three identified as Latino—participated in this study. All respondents were living in Riverside at the time of their interviews. Our institutional review board approval prohibited us from requesting specific information regarding age, income, and length or residence; instead we gave participants ranges for selection. Participants as a group indicated their ages fell between bands of 31-35 and 66-70. Half of participants were aged between 31 and 35 (n=8) or 56 and 60 (n=7). We asked participant income; three declined to provide this information; 17 reported a family income of $40,000 or higher—of those, nine indicated an income in excess of $60,000. Twenty-seven participants had lived in Riverside for at least 10 years; 13 of those lived in the community for more than 30 years, and no participants had resided in the community for less than one year. Participant occupations were split among professional/managerial/business owners (n=14) agricultural/industrial (n=4), retail and service (n=7), homemakers/parents (n=3), and four participants who indicated that they were retired or declined to identify a profession. Occupation total count (N=32) exceeds the number of participants because some identified with multiple professional roles.

We used the grounded theory framework as a method for gaining understanding of the relevant and complex processes while capturing and respecting multiple perspectives. Therefore, we present and consider our results by category as follows: (1) stigma attached to Hepatitis C, (2) community division, (3) how social hierarchy influences people’s perceptions, (4) the increased number of Hepatitis C patients and low income families, (5) community members disregarding the problem of ignored viral infections within the community (6) how social hierarchy is developed in rural communities, and (7) ineffective solutions by the community.
Stigma Attached to Hepatitis C

One participant, Annette, shared her personal experiences with her husband who passed away because of Hepatitis C. After her husband passed away from complications, a member of the school system came into the restaurant where her teenage daughter worked and told her, “You should not be working here because you can give everyone what your father had.” Annette’s daughter heard people were saying her father was a “druggie,” which made her feel as though she should be embarrassed about what had happened.

Annette and her family did not receive any help from the community in terms of fundraisers or financial assistance of any kind to help pay for medical treatments and hospital stays. This was the case during the time Annette’s husband was alive, after his death, and until all of the children left home. Annette said she was “in such a fog” that she did not see what was happening at that time. Now, as she looks back, the “family’s status within the community was impacted” by the illness and death of her husband.

This episode indicates how Hepatitis C can make the entire family perceive themselves as outcasts in the community. It also shows how rumors in a small community play a major role in shaping one’s personal life. This episode also displays how Hepatitis C patients, their family members, and poverty are linked in Riverside—even though Hepatitis C or any viral infections can be found in individuals from a variety of socioeconomic classes.

Community Driven

It became apparent that there was a division on the outlook of Riverside residents. One participant who was a high school teacher described, “Our little town, it loves individuals with a…second chance story” to indicate the community’s high level of acceptance toward people who are new to the community, those who made a mistake in their life, or those who are facing various predicaments in their life. On the other end of the spectrum of how the community is viewed, a waitress described how the regular customers are very distant and not accepting of others. It was only after working the same restaurant for many years that the regular customers began to inquire when she was absent from work. She said, “If I am not at work then it’s like they want to know where I am at and am I OK.”

In terms of how the residents perceive the problems of drugs, viral infections, and poverty, almost all participants recognized they have a large population of people living in poverty in the community. However, there is a difference between how individuals who are in the lower socioeconomic status and those who are in the higher status described the community’s response and responsibility toward these issues. One participant who spoke very highly of the positive characteristics of the community such as “tender or caring” stated that “the negative [characteristic of the community] is the …um… the low socioeconomic. There is a lot of them here. Um…aaannd it’s not by any means the lower economic people’s fault; it’s just there is a lot of it.” While this participant did not blame individuals or families for intergenerational economic difficulties, she sees no obligation for the community to help those individuals. On the other hand, one community member who acknowledges her lower socioeconomic status in the community stated, “They (the community leaders) don’t help people like they should very much. As much as they should.” This participant considered the community’s efforts to ameliorate the community’s various issues associated with poverty insufficient.
How Social Hierarchy Influences People’s Perceptions on Viral Infections Diseases

Most of the participants in this study acknowledged the presence of a social hierarchy system within the community. However, as the socioeconomic status rose to the middle and upper classes in the community, many did not believe the hierarchy system was necessarily based on a ranking order of income or wealth but, as one participant described, more of “a cliquish type thing.” This was evidenced when participants considered who the most influential individual in the community might be and were unable to identify a single individual although they described a group of city council members, hospital committees, and business owners who were “…putting all of the money and effort into the downtown area.” In a sense, this rural community may define social hierarchy based on the level of one’s involvement in the community but not necessarily based solely on the financial factor. Another participant described the people in the higher social hierarchy as “…people that are heavily involved in the community as far as runnin’ for boards of things, ya know, boards of organizations…they kind of basically run the town.” It is worthwhile to note participants described those members of “boards of organizations” in this community as tending to be the elderly residents who express traditional family values and a strong Christian faith. Meanwhile, the lower socioeconomic status is defined as those who are on or have received monetary assistance from the government. Those individuals were more aware of racial factors and class consciousness in the social hierarchy, especially in regard to the community as a whole:

You have your top hierarchy, that is, the top prominent rich, and then you have your…basic, middle class type. And then you have, uhm, your poor whites…and you know, sometimes it is just because they had a lot of bad luck. And then you have your blacks…and…your ones of the Mexican descents…which is actually above the blacks probably.

People in a lower hierarchy in the community see that no assistance has been provided from the community for the lower class, especially in regard to the fight against Hepatitis C. It was interesting that a few different waitresses noticed how the group of people in the upper class “…doesn’t seem to recognize that there is anybody in this community that has Hep C or HIV.” Those waitresses are not the group members of the upper class “clique” in the community, but they had many chances to observe and listen to upper-class people’s conversations at the restaurants where they serve. One of the waitresses said sarcastically: “[Hep C] doesn’t exist [in the eyes of upper-class people]!” This lack of recognition from the upper “clique” impacts the amount of help the community provided. As one of the participants in a lower hierarchy said, “I kinda think it depends on who you are as to who will pull together to do something for you.”

These comments suggested the view that unless the upper “clique” people would “pull together … something” to assist those individuals with Hepatitis C, the community would have no chance to develop any support groups or educational programs to ameliorate the current situation. Additionally, participants believe the “clique” group was more motivated to help based on perceived status over actual need.

Older individuals expressed less support for community-wide education whereas younger participants believed the school-age population and individuals of any age need education regarding infection transmission and treatment. One of the young mothers mentioned the necessity of “starting [the educational program] in the schools” and then reaching out to the hospital physicians.

While over half of the participants acknowledged the need for education for the youth, they believed that it was likely that “no one would show up” even if there was a program
available for the whole community. Participants felt the nature of gossip in a small community would be a disincentive for program attendance; there were fears that attendees would be ostracized if others suspected they carried the Hepatitis C Virus.

**Increased Number of Hepatitis C Patients and Low-Income Families**

Throughout the majority of interviews, many participants were not aware of any individuals within the community who had contracted Hepatitis B, C, or HIV/AIDS. However, a nurse discussed an estimated number of individuals who are carrying to Hepatitis C virus in the community: “…There has been a huge, huge increase in Hep C… at my job we diagnose at least two new people a month.” However, there seems to be a focus on “putting all of the money and effort into the downtown area” to attract new businesses and tourists, instead of using “the resources to educate the community to stop the spread of viruses” as one of the participants described.

A few other participants made references to the community as a “welfare pit” that continues to attract lower socioeconomic status families. According to some local church members, this is due to “how easy it is to gain welfare” in this community. People in a lower hierarchy see that the community’s effort to bring new businesses and tourists to fight against poverty is not working well.

While some residents shared concerns for the increased number of individuals with Hepatitis C and the increased number of low-income families who dive into the “welfare pit,” other participants, such as teachers, farmers, and business owners, tend to have an idealized view of the community. They are confident in the local hospital’s abilities to treat patients who were infected with Hepatitis or HIV/AIDS. In regard to the ability of the local hospital’s treatment, a local nurse stated, “Obviously, we don’t treat. We’re not, you know, a specialist.” She analyzed how community leaders believed that the hospital is more equipped than the hospital actually is. This belief might be based in the perception that the community leaders such as the city and chamber of commerce committee members prefer to spend money for beautification of the downtown area to stimulate the community’s economy instead of spending money for Hepatitis C prevention programs. In fact, Riverside paid a considerable amount of money to invite an artist to paint on the walls of downtown buildings during the interview period. Because the problems of Hepatitis C, drug usage, and poverty are not recognized as problems of the upper hierarchical people, it is not perceived as a primary problem for the rest of the community. This continues to allow the community to spend their effort on surface level improvements such as the beautification of the downtown area. However, the community has not seen an actual increased number of tourists or an economic boom to reflect the amount of money and effort they spent. Meanwhile, increased numbers of Hepatitis C continue to be associated with poverty along with increased numbers of welfare recipients in the lower class. This association might be used by the community leaders as a good explanation of why the community has not improved despite all the efforts of beautification. The increased number of Hepatitis C patients who are perceived as “druggies” may be unfairly blamed as scapegoats for the decision makers’ failure to improve the local economy.

**Disregarding the Problem: Blind to What Is Happening within the Community**

Some individuals, especially those who were in the higher hierarchical group, did not believe there were any problems with the viral infections in the overall community. One participant felt so strongly about this belief that she said, “Because we are…an older community. So we don’t just have Hepatitis, we have all kinds of ailments here with the elderly….” as if the larger elderly population were the safeguard for spreading Hepatitis. A
retired teacher admitted that the community is welcoming because she intentionally ignores any problems. She explained, “Since I retired I don’t get much further than this right here, I don’t see any intolerance. Cause I-I am the ostrich in the sand. If I keep my head buried, I don’t have to know a lot of things.”

Contrary to the community’s leaders such as business owners and city council members who are focused on beautification of the community, some Riverside residents, especially the younger generation, see that the problem lies with how the community’s money is spent. They believe Riverside’s budget plan has not helped the lower socioeconomic families who rely on welfare to no longer need to depend on government assistance. For example, a younger participant discussed that the town had a plan to help create a place for teenagers to go and keep them off of the streets to reduce their chances of exposure to activities associated with juvenile delinquency: unprotected sex and drug usage in the past. This plan should help cut the vicious cycle of intergenerational poverty. However, upon further discussion of building the multipurpose center, it was decided that the community members have to pay several hundred dollars to rent the building for an event, which is not affordable for most people in Riverside. As the rural community continues to exist, the spread of Hepatitis C or any other viral infectious diseases are further ignored and pushed aside. When participants were asked if there was a support group of any kind within the community; a popular answer was, “I doubt there are any support groups here.”

While members of the upper class also recognized the drug and poverty problems, these individuals were less likely to believe spending money for welfare programs or educational programs would ameliorate the situation and expressed preference for improvements to the community’s appearance over directing funds toward health and social programming. Even if an individual with Hepatitis C has not received welfare benefits, he or she will be misidentified as a welfare recipient since the individual and his/her family will fall into poverty due to job loss and a lack of financial support from the government or the community. Thus, it reifies the connection between Hepatitis C and poverty in Riverside.

How Social Hierarchy is Developed in Rural Communities

We have observed that a certain group of residents who gather for breakfast or lunch at a local family-owned restaurant in town after church services and many other occasions. They are the elderly teachers, farmers, business owners, and retirees in Riverside. Since a group of these financially secure, elderly individuals in the community can visit up-scaled restaurants frequently and regularly, they tend to become the opinion leaders. The elderly generation has been living in the community for an extended period of time; they then become the source of trusted opinions. The discussed topics focused on other community members and their personal businesses. By partaking in these topics of discussion, perceptions are built and continually influencing perceptions about community members. The financially well-off elderly generation have more time to regularly visit local restaurants and spend a significant amount of time discussing various issues in the community. It builds informal consensus on those issues. By meeting and discussing individuals that reside in the community, they can also actually contribute to the process of stigma building. The waitresses, who are typically in the lower class, hear these conversations. The community leaders’ frequent visits to local businesses that allow for interaction with a variety of people of different socio-economic levels where their casual conversations and interactions can generate bits of gossip and hearsay that become a part of their community’s rumor mill.

In the age of the Internet, people in the community, as well as a local newspaper, post detailed information on various issues in social networking sites such as the local police conduct review and how this year’s budget will be spent along with the local residents’ opinions
about the issues. The vast majority of the topics in the local newspaper and social networking sites are very provincial. In addition, the local news and sources are more valued than the national or international news and sources. Due to the intentional or unintentional self-seclusion from the rest of the world, even in the age of the Internet, a traditional social hierarchy system in the community continues to value the elderly’s opinions which benefit the elderly individuals with financial resources in Riverside. They are seen as the exemplars of the community who are unrelated to drugs, therefore, unrelated to Hepatitis C or poverty. However, it is important to recognize that the number of Hepatitis C diagnoses is increasing, regardless of age categories (CDC, 2015).

Ineffective Solutions by the Community

Isolated from the rest of society, many participants expressed their views of the rural community as keeping “strong social ties” and “it’s like a big family.” Yet, they also mentioned drugs, poverty, and the “kind of people the community attracts” are the big problems. Financially secure individuals expressed their efforts to provide continuous help for the people in need such as holding “bake sales”, yet one of their main concerns was the level of government assistance going to the welfare programs, which they thought is preventing the entrance of new businesses that might lead into an economic boost.

In comparison, people in the lower social hierarchy felt that they can get monetary assistance if they have visible disabilities or illnesses that are not associated with stigma such as genetic diseases. If it were unseen disabilities or mental illnesses such as depression or extreme fatigue due to the complications of Hepatitis C, then that person is seen as “oh, it’s just in their head or ‘they’re lazy’…they oughta get a job.” It was noticeable that an individual in the lower social hierarchy felt as if the upper social class members are “taking advantage of the lower class rather [than] sharing [the resources] equally among all classes” in terms of how the community is spending their money to “bettering” the community.

Discussion

Based on our review of how rural community members perceive Hepatitis C, how and why they believe the illness is linked to deviant activities, and how they confirm their stigma attached to Hepatitis C, we argue that the community leaders utilize the stigma attached to Hepatitis C to justify their political decisions and positions in the community. The financially stable, elderly community leaders are not concerned with being infected with the Hepatitis C virus while many other younger residents in the community, where welfare recipients are prevalent, witnessed their neighbors, acquaintances, or even family members suffering from the illness. We also argue that the view of a rural community as a “family” is unrealistic and is perpetuated in part by the tendency of people in the upper hierarchy to romanticize rural living.

Typically, with the exception of those who had consistent interaction with individuals with Hepatitis C, the age category “over 40 years old” is more likely to hold the belief that the viral infections are caused by homosexual sexual activities and drug usage in Riverside. They were unaware of other possibilities such as medical procedures prior to the 1980s. Additionally, those participants were unable to identify which groups, such as race, gender, religious affiliation, age, or occupation, are most likely to be susceptible to contracting Hepatitis B, C, or HIV. Interestingly, individuals indicating their age as over 40 knew less about the Hepatitis virus and other viruses than the age group of 30-39 years, suggesting higher age categories did not necessarily represent greater knowledge in Riverside.

The approach on fixing the community’s problems is perceived differently depending on the level of social hierarchy. At the lower level of the hierarchy, people are more likely to
notice poverty and drug problems as the community’s problems. A restaurant manager that is considered to be one from the lower level of the classes also noted that there was a lack of resources to gain help from the rest of the community. Ultimately, many lower social hierarchical individuals felt that addressing drug and poverty issues would lead to more economic opportunities available for the whole community. Because the upper hierarchical individuals are more involved with the decision-making processes in Riverside, the focus was on downtown beautification over effort to break the chains of infectious disease, drug abuse, and poverty.

Clearly, people in the lower class are more aware of the problems the community is facing on a personal level. Those in the upper hierarchy seem to not hold the same understanding as the lower hierarchy members because it is not as easily relatable for them. We observed a lack of what C. W. Mills (1959) called “sociological imagination” among the community’s upper social hierarchy members which makes it difficult for individuals to have an empathetic view toward individuals struggling with poverty or infection. This inability to put oneself in others’ shoes contributes to stigmatizing individuals with Hepatitis C and their families regardless of other contextual circumstances such as one’s financial or social circumstance. With the community leaders’ indifferent attitude toward Hepatitis C and how their opinions are well-respected in the community, it is only a matter of time for individuals with Hepatitis C to be labeled as “drug addicts,” and/or “sexually deviant,” who becomes “lazy welfare recipients.”

Obviously, there seems to be some disagreement on how to promote a positive community image among Riverside residents. For some people, it seems that the community is trying to implement an ineffective solution for the problems. Many businesses in the downtown area are offering new events, small farmer’s markets, wine tastings, and local clothing stores to enhance the economic opportunities for the local people without seeing any drastic improvement on the local economy while no new support groups, programs, or centers for families and individuals in need are established.

This study focused on the stigma building processes and breaking down the factors that build stigma within rural communities that are generally overlooked with previous studies (e.g., Marinho & Barreira, 2013; Treloar, Rance, & Backmund, 2012). The process of stigma building surrounding Hepatitis C in a rural community is developed by frequent interaction with a variety of people in different socio-economic levels. We suggest rural communities need a formal support system instead of relying on imaginary family-like support system.

As for the contributions of this study, we recognized the important role of community leaders’ casual conversations in public places such as local restaurants in a rural community. In such environments, it is not that difficult to find a chance to talk to the community leaders in a rural area. Because of the likelihood of interactions with the upper hierarchical members in a rural community, it is possible to sway their opinions about certain issues by lobbying to gain upper hierarchical members’ support in urban areas.

The limitation of this study includes that our findings were unique to Riverside since all of our participants were recruited via snowball sampling in a single rural community. In addition, there was no confirmation from the local hospital about the official number of community members currently living with the Hepatitis C virus although we were able to get opinions about the prevalence and increasing number of Hepatitis C within the community from the local nurses’ interviews. Additionally, the majority of the participants were female and fell within two age groups: 31-35 years and 56-60 years. There was only one participant in the age category of 36-40 years who was willing to participate in this study even though that age category is a crucial time period for the development of social stigma due to having children in the preteen category. This age group is influenced by current trends and knowledge and the traditional values of their grandparents and parents.
Analysis on social support for Hepatitis C patients before and after the installment of support groups and education within the community may be necessary to suggest establishing new educational programs or support groups in a rural community. In order to implement such a plan, conducting a survey to see if there is a correlation between the level of social support and the psychological well-being of Hepatitis C patients who live in a rural community may be necessary for future study.

References


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