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Abstract

This paper reports the first phase of a two-part exploratory study that sought to understand the challenges of navigating the health care system from the perspectives of post-incarcerated individuals. Phase 1 focus groups sought to understand the experience of releasees and their efforts to self-manage their health care. Three groups of adult men and women, 23 participants in total, with an incarceration history participated in Phase 1 focus groups. Barriers to access identified included: lack of computer access and/or computer literacy; poor health instruction and limited health system comprehension; lack of navigation skills; memory difficulties; homelessness and poverty; poor insurance and perceived bias of providers. Generally, the groups lacked the ability to problem-solve and blamed others for their difficulties while expressing an interest in providing self-care- they simply lacked the knowledge and skills to do so. Natural leaders emerged from the group, and were found to be informal helpers to those being released to the community.

Keywords: *healthcare; post-incarceration; barriers; qualitative;*

Introduction

Over 3200 adults are in some form of community supervision by the Connecticut Department of Correction each month (CDOC, April, 2016); 87% of these individuals are male, and 55% are of minority race and/or ethnicity. This transition to the community is known to be highly stressful as former inmates struggle to find housing, re-establish relationships with their families, reintegrate into their communities, find employment, and gain access to health care (Binswanger et al, 2007). Unfortunately, the focus upon health often takes a back seat to the more pressing issues of housing and employment (Perez, Cummings, Schrag, Mead, Jewers, (2013). This exploratory study sought to understand the challenges of navigating the health care system from the perspectives of post-incarcerated individuals; and, to develop dissemination strategies to support these individuals in their efforts to provide self-care management following incarceration. This paper reports the first phase of this study which includes the perceptions of 23 male and female adults who participated in focus groups with an aim to understand the experience of these releasees with their efforts to self-manage their health care.

Background

Many post-incarcerated adults live in under-resourced communities where people are more likely to be medically underserved (CDC, 2013) and where the risk for disease and infection is highest (Fazel & Baillargeon, 2011). Concurrently, the opportunity for early diagnosis and adequate treatment is at a minimum (Kulkarni et al, 2010). Annually, more than 12 million men and women are released from federal, state and county jails and prisons (Pew Charitable Trusts, 2008). The prevalence of chronic medical conditions is notably higher for those in jail or prison compared to non-institutionalized populations (Binswanger, Krueger, & Steiner, 2009).

Health care provided to persons while incarcerated is estimated to cost approximately 7.7 billion dollars per year in the United States (Reason, 2014). Healthcare vendors, both private and public-private provide limited transitional health care upon release. Health care that is provided upon release is usually associated with transitional housing provided by state departments of correction and lasting 1-6 months post-incarceration (Flanagan, 2004). Like other citizens, the post-incarcerated population must assume control of their own health and health care once in community settings. The challenges to this shift in focus is significant for these individuals who experience both social and clinical vulnerabilities.

While behind bars, incarcerated persons lose their privilege to Medicaid, Medicare and other public benefits making it difficult to regain insurance coverage when released (Mellow & Greifinger, 2007). Although extensive research has been completed on recidivism rates, little has been completed on the reentry process with regard to health care transitions at release from a department of correction. More research is needed, particularly, to understand the reentry process following the end-of sentence timeframe when individuals assume full responsibility for community living (Bahr, Harris, Fisher, & Armstrong, 2010). Depending on length of incarceration among other factors, this vulnerable population can lack both the resources and knowledge to navigate the healthcare system, access services and manage their own health care once back in the community. The association between these abilities and recidivism are beginning to appear in the literature (Patel, Boutwell, Brockmann, Rich, 2014; Fu, Herme, Wickersham, Zelenev, Althoff et al, 2013).

It has been suggested that some releasees will seek re-arrest to obtain medical services (Devereux Whitley, & Ragavan, 2002). In consideration of statistics that report that two thirds of United States (US) parolees were rearrested within three years of release, and 52% of these re-incarcerated (Bahr et al., 2010), the costs associated with provision of chronic disease management is a significant societal issue. Pew (2014) reports that the size, age, and health status of incarcerated populations are the primary determinants of total correctional health care spending. Further, it is reported that distance of prisons from hospitals and other providers; prevalence of infectious and chronic diseases, mental illness, and substance use disorder; and the aging of the population affect the delivery of health care and drives the per-person costs.

The significance of this two-phase study included the use of participatory approaches to explore the experience of post-incarcerated men, women and older adults in transitioning to the community and the support of their efforts in self-care management. As will be shared in the companion article, strategies identified and tested to support individual efforts to take control of their own health and wellness are expected to reducing disparities faced by these individuals.

Methods

This 2-phase study sought to partner with persons who had an incarceration experience to understand how to successfully disseminate findings from health research in a manner that would be acceptable to the population for use in their lives. The goal of Phase 1 was to engage the participants and to assure that we understood the needs of the population and their preferences so as to properly target our messaging to facilitate uptake of health information (usability) to promote self-care management.

Phase One Sample and Data Sources

In phase one of this study, a total of 23 men and women with a previous incarceration experience participated in four focus groups. These focus groups were held at a local reentry agency. IRB approval was obtained through the University of Connecticut Human Subjects Review Panel (IRB # H14-103).

Recruitment and Consent Procedures. Participants were recruited through the distribution of flyers by agency staff. The researcher followed by presenting informational sheets with question and answer sessions, followed by individual consent procedures for those who volunteered to participate. Criteria for participation included: 18 years of age or older; cognitive and mental capacity to participate; previous incarceration experience; English speaking and comprehension (there were no translators available); adequate hearing (no hearing-assisted devices available). No identifying demographic information was collected during this phase of the study. Participants were excluded from this study if they were unable to agree or understand the guidelines of the group due to mental or developmental delays or confusion. This was determined when giving consent by having the participants describe their understanding of the research study, ask questions and discuss their proposed contributions to the project.

Focus Group Methods. There were two preliminary and two follow-up focus groups. Focus groups were separated by gender and lasted between one and two hours. Ten men participated in the Phase 1 male focus group and 13 women in the female focus group. The focus groups were led by the same group leader each time and a semi-structured, 18-item guide was utilized to direct group discussion. Questions were developed prior to the groups and were based upon a review of the literature and agency administrator input. The questions guiding the focus group included the following items: facilitators and challenges to access to health care as they transition to the community; facilitators and challenges to access to health care information; preferred method of receiving healthcare information; and types of information needed, or most useful when in transition.

Each focus group began with group defined rules which included: respecting their peers, taking turns, keeping confidence and maintaining social behavior. Participants were also aware that if suicidal intent was revealed, the person would be referred to staff. Each focus group was audiotaped for later qualitative analysis and transcription. Nutritious refreshments were provided during each group and participants were compensated with a $25 gift card.

After the first set of focus groups were transcribed, two follow-up focus groups also separated by gender were held to with the original participants to validate and interpret the findings. Responses were read to members who discussed them. Quotes were placed on cards and provided to group members who sorted them into groups and named them. The combined categorized responses are reported here.

Findings

Sample

Ten adult males and 13 adult females (n=23) aged 21 and older participated in gender specific focus groups. No other demographic information was collected. Participants self-selected into one of three age groups held following consent procedures.

Themes

Ten themes were identified from the review of transcribed text, and confirmed by participants in follow-up groups. Participants assisted to modify the theme names.

Theme 1: Time Spent Waiting for Healthcare

“Waiting” was a frequent description by both men and women as they described their experiences with healthcare services while in jail or while living in the community. In the state prison system, a request to see a physician or nurse could take up to fifteen days for a response. As men and women talked about waiting for healthcare when they were incarcerated, they described difficulties, especially when care was more urgently needed. Dental care was the most difficult to access and mental health care appeared to be addressed quickly.

> Female participant: *"I think it also depends on what you are being seen for because you have dental, you have eye care, and then you have your regular physical care. I mean it all depends. I mean they will call you for mental health quicker…Quicker than they will call you for anything else as far as health, appointments, dental, eye. I waited up to two years to see the eye doctor."*

> One participant described his experience as: "*We file these requests. These are all requests…their medical is so backed up that they can't even tell you what the wait is."*

Several persons agreed that their access to care was unsatisfactory. The way care was managed had a dehumanizing effect upon inmates. One participant went on to clarify:

> *"Well what he is basically saying is a lot of time they don't really care about you. You are basically like cattle. You got a number; they got to move you along…you can write all the requests you want and you might get answered, you might not get answered so they really don't care so…"*

Prior to end-of-sentence, some incarcerated persons are assigned to live in half-way houses as they transition to community living. As halfway house residents, their experience with 'waiting' is no different. If healthcare is needed as a halfway house resident, the individual returns to a medical clinic located at one of the prisons throughout the state. Inmates do not like this arrangement, they fear losing their halfway house bed. This in turn acts as a barrier to whether or not care is accessed.

> One person described, *"it's not serious but you go to [facility] at this moment and ask them what the wait list is for medical, if you are not bleeding and you are not in severe pain right now that they can see…. you could go for…its two years."*

Another group participant responded:

> *"Instead, men and women can be asked to either wait for another bed to open up or some type of release again, requiring the whole thing to be repeated. Who volunteers to go back?"*

And another group member agreed:

> *"More prisoners than halfway houses, it's a wait- causing folks to go through the whole process of coming out"*.

Theme 2: Discouraged from use of care

In addition to waiting for services, men and women perceived that their health care needs were unmet. This sense of not having their health care needs met was a common theme across settings- while incarcerated, while living in halfway houses or in other community settings, and during the process of transitioning to the community. Participants perceived staff indifference and inattentiveness in addition to limited access both to healthcare services and to health information. Notably, participant's perceptions were influenced by the effects managed care had upon their use of care, perceived as 'the sickest are cared for first"; "issues with co-payments", and slowing access to reduce utilization.

> Male participant: *"if you really don't have money on your book, they really don't get to see you, you know what I'm saying? or, if you have money, I think if you have money on your books they will see you quicker".*

> Another participant stated*: "You could go [to get medical care]; you put a medical slip in and they charge you three dollars. And you could go in there and say I have this issue and they say 'okay well we charge before we do any treatment. Sign this paper…its three dollars.' Every visit, no matter if they see nothing…excuse me…or they refer you to the doctor you still paying and you have no treatment that you are paying for. So we charged for no treatment."*

Participants had concerns regarding access to emergency services: one person described:

> *"you have to be really dying for them to really like just take you and take you out to a hospital".*

Another person felt they could not access emergency services until they were released. They describe:

> *"I had pneumonia, spitting blood ... I'm spitting blood, I'm sweating for two weeks three weeks. I had to bond out of jail just to go to emergency room. I went in there [to the ER]. I was in there ten days…This is the kind of stuff they do [had to bond out of jail to go to the ER] and I got like documentation of this stuff."*

Another group member described another inmate who had seizures but declined seeking services he was in need of.

> *"He was um feeling weak and they said, 'can you walk.' And he said 'yeah'. If he is telling you he is weak and you know he don't feel good, you gave him the option to walk. He is not in the right state of mind so he chose to go with whatever he*

> *thought he can do and the minute he went to roll over and he was- well, he had seizures. Ya know- you get hurt or something happen and then they break it all down, oh this…they only give you the treatment that you ask for … the medical part, if you're not bleeding, if you don't have…if it's nothing they can visually see then you aren't being seen. So he figured he could walk. When that dude so happened to just make a move he fell, hit his face. He knocked out all his front teeth, then didn't know what happened to him and he had like a minor seizure and then didn't even know what happened to him. It ain't right- know what I'm sayin?"*

This story seemed to resonate with the group of men. One participant wanted to share a solution he figured out:

> *Sometimes 'who you know' can get you through the door of the medical clinic. I had stopped the lieutenant one day on the walkway and um I explained to her my situation. ….But the lieutenant did send me over there. I did get seen that day."*

Another person agreed with this strategy:

> *"And I have a friend of mine that I have known for years that works there and anything that I need to get done and he is working he gets it done…… He [friend] puts his hand in and makes a phone call for me if I really needed it [healthcare service].*

One additional participant stated:

> *"If you're not affiliated, word of mouth, some counselor, you know, puts a little bug in your- 'hey, don't saying nothing but I'll look out for you' then you don't have nothing coming."*

Theme 3: Rights and Respect

As men and women participated in the focus groups, several reflected on what they thought important. Some of the participants reported that they had been involved in grievance processes while incarcerated, and described the importance of human rights and personal respect.

> One participant noted: "You want people to not just speak at you and tell you what these issues are, but to actually hear you. These people who had my life in their hands for the last five years… hear what they have to say, because I was just like your son or daughter… I was somebody important but when I brought my issues up you didn't address them."

A strategy participants utilize when they felt they could not tolerate how they were being treated any longer was to write a grievance.

> *Male participant: "When I wrote the grievance…sometimes if you write a grievance it is to the point where if you write a grievance they will ship you into another jail."*
>
> *Another male participant: "Yeah. We all entitled to the medical…Yeah, I know, but I did ten years. I did ten years though and when…the thing with the grievance process, if you keep pushing the grievance process you get transferred."*

Participants questioned why they had been exposed unnecessarily to health risks while in prison, and viewed this as another sign of disrespect.

> *One male participant reported: "Like I was in the hospital and it was asbestos and they were still doing it while we were still housed there, [while incarcerated] to clean up the asbestos where we could be exposed to it at all times."*

A male participant who had asked to be tested for the sexually transmitted disease before release, and was denied his request added:

> *"This is what would be really important to me- that if I get sick now that I am back in the community, or give somebody something, I would like to hear them, have a conversation with them about when I asked you to get a test for STD and your staff wrote to me and said that they will not do that because I have to show a sign or symptom. I would like to know since you are in charge and that request went to your desk that was signed off your supervisors or whatever."*

One person described observing that a person was placed in the same halfway house as he was in, but he could not go up and down stairs- yet the house had no elevator. He questions why this happened:

> *"If you got sent to that house and you can't walk up the stairs that's it, they send you; they send my boy back to jail because he couldn't make it up to the third floor. That's rid…that's crazy… and they knew he had a medical issue when they sent him there."*

Yet other participants had positive experiences and were grateful for this, believing that staff participation and facilitation of a re-entry program comes from a feeling *'in your heart'*. For those persons who had a good experience getting assistance, one male participant stated:

> *"That's why we love this program so much because the people in here- the way they treat us".*

Theme 4: Some are ready- some are not

Men and women interviewed had mixed perceptions about having received information regarding health resources or health information prior to their release. One person stated:

> *"as far as the information part goes when you leaving prison, they don't give you any information."*

Yet others had different experiences and shared that receipt of information was influenced by how these individuals were released.

> Male Participant: *"Court or OTS or parole, you don't get none of that stuff. Only when you are discharging [get discharge packet], for others who transitioned from the halfway to community living, you know- end of sentence, I came out to a half-way house, they gave me a bag".*

The uneven preparation for release was reported by other participants who felt the communication of their release plans was poor.

> Female Participant: *"For me to find this program right here too, I had no idea when I came out of jail this program was here."*

> Female Participant: *"Yeah, cause the thing is you guys aren't there when the guys are leaving or getting ready to leave so there's no information being given to the guys 'cause most of the people there don't really care about them".*

Factors contributing to this uneven preparation for release may have been tied to specific facilities. A male participant reported:

> *"It depends which prison you were released from, whether or not you got with a discharge planner and also depends on what you are being seen for- the kind of problems you have."*

> Another male participants described: *"No, like it depends on like um if you have to be seen by a doctor on the side then you see the discharge planner, but other*

> *than that you just get placed in a half-way house and if you need to see medical you need to go back to [state prison].*

Another participant just considered themselves lucky that things worked out. This participants stated:

> *"Well I actually lucked out because when I was discharging out, the discharge planner called the clinic, put my medical care in."*

Some of the participants understood the importance of having appointments with other health care workers or counselors prior to release, and that follow-up with them was a way to access services and information.

> Female participant: *"you need to get connected before you even come out because if you aren't connected before you come out it's a struggle and you already have to deal with the rules of the halfway house to get connected."*
>
> A second female participant agreed: *"True, because I lucked out, like her. When I came home I had an appointment already set before I even left the compound. My medical insurance was already caught on before I even left the compound so I was lucky- I lucked out too."*

For men and women who did not go to a halfway house as a transition before release, there were other resources. As one person described:

> *"I didn't go to a house or a half-way house. I went to the Y and when you get there, there is a doctor that comes there once a week from [community agency] and that's how everybody just gets connected right then and there."*

Another participant added:

> *"For me it was a lot easier than I expected, but it still can be difficult trying to find the right providers to take your insurance."*

Theme 5: Ready or not - First days out

Men and women described major stressors during the first days after release. Generally as a group, they were feeling ill-prepared and un-supported at release to the community. One participant described what he saw after he was in the community:

> *"I walked out seeing the bus pull up, I see they just drop this guy right off, same like you said, you see what I am saying? And, you got people that come from jail and just get dropped off in front of [community agency] or [agency] or the shelter. Why is that? That's what I want to know. It shouldn't be like that. They have absolutely nowhere to go."*

One person described how minimally they felt prepared:

> *"Like initially we would come out with a bag and that's it, ya know? And two weeks of medication."*

A female participant described her anxiety about difficulties getting linked with services:

> *"There is a lot of places that just won't, ya know, they give you the run around, they just won't take you."*

For some, healthcare access was a challenge because they were not connected to insurance or health providers. Others thought if they had information regarding healthcare resources and knowing which healthcare providers were taking patients, their transition would have been easier. Much of the emphasis focused on assuring that we understood that those who needed healthcare most likely returned to a medical clinic at a prison site even though they knew they ran the risk of not coming back to the halfway house. Although access to Community Health Clinics (FQHCs) was available to these participants, they perceived that if they were under supervision of the Department of Corrections, they had to goes back to a prison for their healthcare needs.

As this misconception was further explored, it was apparent that participants lacked knowledge of and were uncomfortable with the community health system. One woman commented:

"Like coming out it was really, really difficult to get connected to you know, different places to get treated."

Another halfway house resident, responding to the discussion regarding resources provided to them to assist with their transition stated:

"We have no access to anything, to any information."

However, one man, who after release became a program volunteer in the community described their role in helping others transition out of jail or prison:

> *"So it's the first thing they ask me as a volunteer. I have to comfort them, make sure they alright and give them information where they can go and who can help them."*

Regarding resources available in the halfway houses, both male and female participants agreed that there were limited healthcare information available, and little information was shared about what the halfway house had to offer. Some knew that packets of information were available, but when we asked further only one of eight participants received a packet of information prior to release. One person described that they learned what the halfway house had to offer, only when they arrived there. For others, their experience was even worse:

> Male participant: *"Nobody even told…nobody told, I was in the house for a month, and other people at the halfway house right now doesn't even know this".*

The general consensus was described in the words of one man:

> *"Ya know we are not connected to insurance coming out, especially if you are end of sentencing and you know, coming out into a half-way house or something like that."*

Three men and women, when asked if each had access to information about insurance, or medication, replies 'yes' they did. Their descriptions suggested that their access to insurance, and therefore services took some time to unfold. One participant described her experience:

> *"I'm on, like you said special parole, I'm finally seeing, I've got doctors and stuff now through [agency] because I went in for the MRI but like they said if you are on DOC forget it. Now, they finally gave me the Husky, so now I am getting seen."*

Other men and women transitioned to a halfway house with an assistance program already in effect. As one person described, female participant described:

> *"I got my insurance as soon as I was at the halfway house like a week later I had my insurance card". True, because I lucked out, like her. When I came home I had an appointment already set before I even left the compound. My medical insurance was already caught on before I even left the compound so I was luck- I lucked out too."*

Poor communication and the discontinuity of services associated with system functioning appear to increase the level of anxiety among transitioning individuals taxing their coping capabilities.

Theme 6: Released but Not Free

Fear of remand to jail or prison was reported to be influencing choices these men and women were making with regard to health care. One person describes his efforts to avoid reincarceration as he relayed an experience he had with a prescription that was not right for him and was not changed. He stated:

> *"I talked my way out of it, the lady told me, she said if I let you go, will you take your medication? So I told her what she needed to hear. I said yeah I'll take it but I take it off and on but I know that medication ain't right for me because you shouldn't have to take no medication and you urinating every minute every minute every minute something ain't right with that."*
>
> *"And then the second time they called me back how was I supposed to have went there? So I was like listening to you guys like the people that got jammed up, they ended up staying you know because what they were saying with the three month thing or the month thing or whatever, I am so glad that hadn't happened to me, but I was scared not to go. I am being honest with you."*

Other stories included how this process acts as a barrier to care:

> *"Like I know a dude in a halfway house…this dude was living in a room with me, he was having some type of leg pain, whatever reason it got so bad he couldn't walk but he refused to go see them because if you go see them he goes back incarcerated and he has to either wait for another bed to open up or some type of release again, he has to go through the whole process of coming out so I see a dude sit with pain".*

Another male participant shared his fear that if he returned for care he would have to complete his sentence in the prison because he was close to the end of his sentence. He stated:

> *"So you might end up going there and they are like 'ya know what? You got three months to max out…we aren't going to have a bed in another month so you maxing out, you just gotta stay there."*

Another participant reported that a resident he knew literally tolerated extreme pain to avoid going back to the prison for health care. He commented:

> *"I seen a dude stay in pain for, literally to the point they had to take him. He couldn't get up to eat his food. That's how much you don't want to go back to jail."*

> He continued- *"If you are DOC halfway house forget it you, you'll go back to jail just like they said, that's it, no… I know going to buy Motrin or I'll go buy something, Motrin or whatever, because if I don't and you go to them under the DOC, you have to become incarcerated behind a cell door to get help."*

Going back to prison for health care had other ramifications in the opinions of participants, they had too much to lose despite their need for health care.

> Female participant*: "Say we each need treatments like your group or different groups that we go through- we go back we messed all of that, or say you have a job, you just lost everything you just worked for…"*

In response to this, another group member reflected:

> *"And all you went in for, say you got a wisdom tooth, everybody gets them. Something simple that we all get; and like say Obama care, if everyone was entitled to medical why do we go back to jail for it?"*

In our discussion with participants about how they access health information and availability of community services, continuing restrictions were described. Although less restrictive than a prison setting, restrictions in the residential placements include limited access to computers. Further, participants were fearful of using public access computers in libraries because of restrictions for persons having histories of sex offenses. As one person describes:

> *"No, we don't even have a computer in our house and there are forty of us."*

Men and women described limitations related to use of a smartphone:

> Female participant: *"because obviously people don't always have access to them."*
>
> Male participant: *"As DOC you are not supposed to have a smartphone at all because it gets taken from you."*

Another group member agrees, feeling that the system works against any efforts people make to act on their own. He states:

> *"Yeah, we are, where we at its very inaccessible to anything like they just shut everything down like it's just kind of difficult to really get the help that you need because every chance we try to get help its shut down."*

Theme 7: Experiences Managing Health Problems

Men and women described both chronic and acute health problems and their efforts at self-care. The stories were varied, but there are clear indications that self-care interventions could improve the health status of many of these individuals. Areas mentioned repeatedly that could benefit from focused self-care interventions are medication adherence and recognition of symptoms and knowing when to initiate action. The following stories are examples:

One man had fallen off a balcony, and *"had 117 stitches"* and *"a liver problem"* resulting from the fall. He was prescribed medication, but reports *"...but I don't like taking the medication"*. Another person described *"having an ear infection"* that went unrecognized and untreated. He related that he *"thought my eardrums had busted, but they had popped."* Another person after *"spitting blood and sweating for two - three weeks"* described having:

> *"Pneumonia and I had start losing weight so rapidly to where I asked the lady to admit me into the hospital, which I went to the hospital and when I got there I was sicker than I thought that I was."*

Several people described mental health concerns, including a history of addiction; and have an opportunity for treatment at a local hospital and other community services. But in the discussion regarding management of pain, one woman reported:

> *"Ya know, some folks are concerned 'bout takin meds. Ya work so hard to get off stuff- ya know? Ya kinda worry what'll getcha going again."*

Theme 8: I can do this, but I need help

Generally, participants stated that they felt they could take care of themselves, but didn't understand what to do. There was much frustration expressed, particularly when individuals followed, what they perceived to be the direction they were given.

> Female participant: *"Like coming out it was really, really difficult to get connected to you know, different places to be treated. Like initially we would come out with a bag and that's it, ya know and two weeks of medication."*
>
> Another female participant responded: *"You have to actively seek it out and there is a lot of places that just won't, ya know, they give you the run around, they just won't take you. Ya know, okay you need a primary care doctor coming out, but some of us need more help than others, ya know we are not connected to insurance coming out, especially if you are EOSing (End of Sentence) and you know, coming out into a halfway house or something like that."*

Group participants described individual efforts at self-care and recognized that the choice for self-care was up to them. As one female participant described:

> *"They help you get connected so without their help, ya know, the choice is yours at the end of the day. You know, you make a choice."*

Other participants struggle with thoughts of balancing what they needed, what seemed to work for them, what was prescribed, and then the costs associated with care or medication. As mentioned earlier, these participants were acutely aware of the importance of insurance. Their struggle to understand how to put the pieces of health care together was described in one man's response:

> "*I take Advair, now this works now they are giving me because you know now I pay for it now they are giving me some twister and I'm telling them it don't work but that's all you guys will pay for. Now that's crazy when like the same thing you said there is certain medication you gotta have and they are giving me some kind of thing that doesn't even dispense the medicine. I gotta actually go get the Advair. It is $200 a thing but that thing works for me to breathe."*

Another male participant described his frustration when he made an effort to do some preventive care. He described requesting a test to determine presence of a sexually transmitted disease prior to release. He reports:

> *"In the prison I had been down for five years and I was going home for a valid reason to start ya know back into society, I figured just have my paperwork adding up and you tell me you don't do that because I need to show you a sign or symptom".*

The participant who works as a community volunteer had a different perspective on why it was so difficult to transition back into the community. He added:

> *"I work in the community so much, it's just, a lot of people are over whelmed. They, we don't deserve second chances; you know what I mean, by coming out into the community. You understand what I'm saying?"*

Theme 9. So what's is the solution?

Group participants stated that they wanted to help themselves and others and agreed that a way to do this was to share health and other types of information with both men and women in prison and also once released. One man supported the "inside-outside" approach that is now being adopted by many states to support a more coordinated effort for transitional care (Friedman, Taxman & Henderson, 2007). In his words:

> *"Staff could communicate with the guys that are preparing to leave, let them get in contact with you before they leave and you guys could assist them before they leave".*
>
> His group members agreed: *"to inform the list of inmates that are about to leave, you [can] make a difference there".*
>
> Another participant thought: *"In each town should have a representative go to the jail at least once or twice a month just to follow up on what you can and what you can have and what you can't have. Stuff changes, how'd you know?"*

When asked what information would be helpful to have, responses included information regarding healthcare providers, medication, medication interactions.

> Female participant: *"Primary providers, medications like what medications are available because you know they are always substituting something, um all of that. The side effects, definitely, everything about that medication especially when it comes to medications because you might be allergic to something that they are substituting inside that medication."*
>
> Male participant: *"Um services provided, contact info, and um drug interactions…I mean I don't know maybe I mean, maybe a couple of programs, you know what I mean because that's the most important thing right now…to get back on your feet."*

Many of the men and women voiced that they did not get any information before leaving prison, or while living in a half-way house, they offered suggestions both for the improvement of programmatic functioning and also for the direct distribution of health related information.

> One male participant suggested: *"Ya'll need a hands on person and you need more than just one [person]. Men and women realized that after release from incarceration, there are differences in where they go; some go to halfway houses, some go to other residences in the community, stuff is different each place. You know what I mean?"*

Another participant from the men's group agreed, but added a caution:

> *"It would be great if they could come into the jail and tell you about stuff they have, and about how they can go about providing information to other half way houses because it seems like she is doing a wonderful job at [agency] but I'm from [another agency] and our halfway house is no one is here, no one even knows what is going…"*

We asked participants to assume they would receive health information; what ideas did they have about how it could be distributed so that people who needed it would have access to it.

> Female participant: *"Make that information on the intake [to community placement] because it is mandatory for them to do that intake. After that you are on your own, but at the door you get that intake and its mandatory and you have to sign those papers that you did this, this this, that."*

A male participant supported just distributing at the community sites:

> *"If it's something that can be brought to the house then it can be passed around."*

One of the men talked about the assistance he received from a program, and felt services could be advertised better. In his words:

> *"[Agency] has a phenomenal program because I have been here a long time, you know what I mean? And they help you so much that right along with [names other agencies], all these programs help, but you gotta have somebody out there to advertise you all, ….*
>
> *"I mean- just to go out, a representative, that's what I'm getting ready to do and I am already doing it because I'm out in the community. I am at the worst spots in [city] talking about [names agencies]. This is just me, but I'm thinking there could be someone that ya'll could have…"*

Other suggestions for distribution of health information were to incorporate it into the standard of care so that it was routinely provided to everyone upon intake to any community placement. It was also suggested that materials could be left in the housing placements so that they were available for use by residents when they needed them. One male participant stated:

> *"Make sure they know that they have to include that on the intake so ever person that comes through the door or out the door to another facility, it is automatic that they received it and make sure… That's easy, just write it in the paper. Some of us prefer having something in writing."*

Another participant had a similar suggestion:

> *"But if you come in the door it is automatic, you get weighed, you get this, your blood pressure, all of that and we are going to sit down and do the STDs, did you get this, did you do this? And then you, see right there, it's automatic. You can't look over it, they gotta do it. They gotta sign it to make sure we got every information that you just provided".*

Some participants who were familiar with how existing programs worked confirmed using this approach. Another male participant said:

> *"You know programs have packets made up so they can give 'em to the guys when they first come home so they'll have all their resources right then and there- so why not?"*

Communication with residents was identified as important, but communication between agencies was mentioned as well. As one man states:

> *"Just get all the information out there, get it into programs like this- you know halfway houses." Yeah- so they can all get together and exchange information about how they can go about doin' it- providing information to other half way houses."*

Group members were asked what information was most important to have that would assist them to access health services. Suggestions included having *'a phone number available to contact'*, or a *'a hotline or something'*. Participants interpreted 'access' as making contact with someone to request a healthcare service. Their suggestion was reflective of the system they had learned while incarcerated (drop box), but also compensated for those persons who did not have cell phones. Having a mechanism for filing complaints if service requests were not met was also important. One man suggested the following:

> *"If you guys reach out to these houses or places- you have your own drop box and then you have a representative come here and actually have a hotline or number where they can call if they feel like their response hasn't been met from the drop box or other than that."*

Another group member continued:

> *"It would, yeah. That coincides with the drop box. Say you guys came and got the information".*

Further exploration of how to best communicate health information, and to communicate evaluation of service was discussed. For some, to access information, they went online *'if allowed'*. One male participant said:

> *"A website for when you are getting out, but a newsletter..." Websites would be good."*

Other participants cautioned us about the use of the internet. One male participant stated:

> *"I think, I think, you know, the newspaper, the internet, because you know some people come out and they can't even use the internet".*

Another male participant offered:

> *"But then again you gotta think about the people who are computer illiterate...well that's why we would have multiple options."*

And another agreed:

> *"I think if you add the website there were people who do have access to the website that can go online..."*

The idea of using an interactive gaming program for the distribution of health information was introduced, to which at least four group members responded 'yes'. Men and women who were familiar with the use of games for learning purposes appeared to have been in the community a longer period of time. For those who had used gaming approaches, there was much enthusiasm. One female participant said:

> *"That would probably interest a lot of people because that would be like you have to interact with the program to learn."*

Another female group member continued:

> *"Yeah but that's because I've been out for a minute and so you know I have access to them things [gaming], but there are people that are here that haven't been out for a minute and don't have access to that."*

Another female participant mentioned:

> *"I play a hospital game on the computer now."*

And another female participant offered:

> *"I play on my phone, on my tablet, on my computer; everywhere in a room in my house I have some where I could go play a game."*

For others, there was great support for televising health information. One male participant stated:

> *"People watch TV so much that, you know some of us watch TV channels like CPTV like certain things. Like I watch the news every day."*

Another male participant agreed.

> *"I don't watch like reality shows so you put it [health information] on TV I could take the number down. If you want to do something to learn something, you are gonna write it down and call. The opportunity to 'write it down' after viewing was important for several persons."*

Another male participant responded:

> *"But if you don't, if it's not on paper then you might not ever get the paper, but if it a flash or a commercial break and it is saying something that interests you, I mean I don't know".*

Participants went on to say that they also wanted the materials in writing as well. One male participant offered:

> *"Both, listening to this information or .... reading it, because you can hear it but you can forget. If you have the material you can go back to it, but its best to hear*

> *it and have the material [written] because you can explain what some people may not understand".*
>
> A female participant added: *"If we had a newsletter or something it would be easier because it can be passed around the house and everybody could get the information instead of having to all make passes and take the buses to get to a computer place. If it something that can be brought to the house then it can be passed around."*

Another man in the group reminded us of the importance of readability. In his words:

> *"A lot of them don't speak too much good English, a lot of them can't read, a lot of them can't write. This is the services that inside and outside should have."*

People in both groups were in agreement that multiple forms, audio, visual and written would really be the best, so that everyone would have what they needed. Many explained that it would be helpful to hear the information, but often times they don't have the ability to write down the information and thus can easily forget phone numbers, names of healthcare facilities, etc. Also, participants said some were visual learners and others learn better through listening. This was summarized in the following comments:

> Male participant: *"Yeah, a flyer, a newsletter, written so we got it in ink."*
>
> Female participant: *"I think, you know like all three because some people are visual learners. Even if they can't read a sheet, they remember what it says and they bring it with 'em. They point to the information they need. It makes 'em feel better haven' it."*

Theme 10: Let's Take Action

The group concluded that there was sufficient information to move forward; both a written and a visual/audio dissemination strategy was decided upon given the budgetary limitations. It was decided that the next step was to create a flyer and CD that included "free" healthcare services available to assist those who were initially getting out of jail or prison. Once a flyer was drafted, this was reviewed by participants. All the information was considered pertinent and nothing was removed. Participants made suggestions about how the flyer could be distributed and posted.

> Female participant: *"I think, personally, I think that this is good though, you know what I mean because like a lot of folks, you know what I mean, don't know what to do when they come home because you have a lot of people who have been in there for years and don't even have a clue as to how to begin to live in society and this is a big help."*
>
> Male participant: *"I mean yeah, it's pretty much everything is here. It talks about medication. There is a number for health insurance. There is also a number for crisis prevention. And then you got at the bottom the number for transport, which is more important because right now people are having problems to get like bus passes, bus tokens…but you have to understand, just coming home, you don't always have access to that."*

Participants contributed to the development of the CD, suggesting content, that the spokespersons should be an ex-offender, and to have a Spanish translation.

> Female participant: *"…An ex-convict…because they can, they will relate more to us because we have been there, done that and we are already out here or whatever you know doing what we have to do and do things like this so…it's more trusting."*
>
> A male participant thought: *"I think it should be a doctor, a nurse, and an inmate…I think it's more relatable when there is, when you can identify with the person in the video ya know. If it's just a doctor you're like ya know you see doctors all the time. If it's like a nurse you are probably thinking the same thing 'ah what does she know?' or 'what does he know?' And if you see a person who's been incarcerated you will probably stop and listen."*
>
> Another male participant agreed: *"…I think they will understand because they know we have already been in that predicament, you know what I mean so especially a lot of times when you see the commercial you may be like 'oh wow, yeah I did time with him…'"*

Participants further felt as though the gender of the spokespersons did not matter as much, but that the telephone numbers should appear on the bottom of the screen.

> A female participant: *"I mean I think they will listen to basically um anybody that has been incarcerated that can tell them anything about this type of program. You know what I mean? Whether it be male or female."*

In collaboration with these participants, and within the limitations of our small budget, we were able to create CD's highlighting two participants who volunteered as spokespersons- one EOS African American male and one EOS Hispanic female. The flyers and CDs were provided in both English and Spanish languages. These communication vehicles told transitioning inmates about how to access the free services available in the community. These services included a crisis line; community health centers; transportation; medication information/assistance; insurance information/assistance; and reproductive services/counseling.

Phase 1 Summary

Through the focus groups held, barriers to healthcare access for the post-incarcerated population were revealed. These barriers included: lack of computer access or computer literacy; poor reading comprehension; poor understanding of how the healthcare system in the 'free world' functioned; and lack of navigation skills. Participants admitted that they had memory difficulties, and their homelessness and poverty made it more difficult to focus upon and deal with health issues. Overall, they recognized the importance of insurance, but did not know how to use it, and had a heightened sensitivity to what they call a bias by providers. Participants stressed a need for healthcare information in oral, visual, and written formats. A combination of these formats will help to address the literacy and cognitive-behavioral challenges of this vulnerable population and their preferred communication styles which in turn will support their learning.

Several things stood out to us in this process. There was no discussion about family members by participants, but clearly their community of support by their peers was important. This natural network of personal contacts appeared to have formed in part by their shared incarceration experience, as well as by their shared community housing arrangement. They relied upon one another as resources and as sources of information. Strong social networks can encourage healthy behaviors. This is important in the development of future interventions.

It was striking about how limited their knowledge was about navigating the health care system, and how passive their problem-solving strategies were toward addressing problems of healthcare access. It should be recognized that these individuals, for the most part, had one foot in the correctional system and one foot out, which may be limiting their level of confidence to manage their own care- even if they do it poorly. They are acutely aware of externally imposed "rules" and the real consequence of re-incarceration hanging over their head if they misstep. While these "rules" are in place to restrain poor behavior, they are having the secondary effect of restraining positive health behaviors as well. These individuals appear "stuck" in place, in part by their own behaviors and in part by how transitional systems are designed.

Once we got to the participatory effort of creating tools to pilot test (see Phase 2, Shelton & Mackenzie, 2016 this issue), these individuals got enthusiastic about the possibilities and embraced the project. Several EOS individuals who had been in the community a longer period of time emerged as leaders and were encouraged to assist further in Phase 2 of the project (pilot testing the CD and flyer).

Limitations

The limitations in funding and the 1-year timeline of the small grant altered the natural tempo of the project, limited our ability to further incentivize individuals to return to participate in both parts of the study, or to follow individuals longitudinally. Despite limitations, we did achieve our goal of determining how to tailor messaging so as to disseminate information regarding access to health care services that were perceived to be useful to this population in this community. The next steps will be to pilot test this intervention and to examine self-care outcomes.

Conclusion and Future Study

This exploratory study was to identify perceived barriers and facilitators to access health care upon transition from jail or prison and to discover which communication strategies would be preferred to assist the post-incarcerated population gain information and facilitate self-care management in the community. Twenty-six men and women who participated in focus groups shared that some of the experiences they had while incarcerated (i.e. long waiting times and poor communication) existed in the community as well. These individuals were living the consequences of the fragmented health care system, exposed to the burdens of poor preparation for release; poor or incomplete knowledge and education; and what was perceived as disrespect by providers. Generally, these transitioning individuals live the reality of there being more consumers than available services and available housing. Instead of embracing the opportunity for wellness, these individuals perceive health care to be associated with losing their housing placement and being remanded to jail or prison.

Despite these challenges, a ray of hope lay in the natural networks that had formed and the individuals who had been out of prison six or more years who volunteered to assist others in their transition. A study of these resilient individuals would be well worth the time and effort. They are well respected by their peers. Despite their strengths, they too were uninformed regarding the ‘free services’ we brought to the group. Keeping a core group of natural leaders well informed and competent to provide support to peers may be an effective strategy for under-resourced communities (Wang et al, 2010). Determining an approach to turning this volunteer work into paid employment for these individuals would strengthen this type of programming and enhance retention of transitional peer assistants.

These transitioning individuals are among those described by Perez et al (2013) who are both socially disadvantaged and chronically ill, and served in the ‘safety net’. As these authors point out, tailored communication, team-based care that is customized and personalized to the individual’s needs, and addressing the specialized needs of this population while using real time data are facilitators to delivering quality and equitable care to populations that continue placing a substantial burden on the social and health care system. This subgroup of persons transitioning from jails and prisons, referred to as “super-utilizers” are among those individuals whose complex physical, behavioral, and social needs are not well met through the current fragmented health care system. As a result, these individuals often bounce from agency to agency, to emergency departments and including readmission or institutionalization…” (Hasselman 2013). The gap is on effective strategies *in* the safety net around caring for chronically ill patients at risk for health and healthcare disparities.

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