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# "It's so simple!" Lessons from the margins: A qualitative study of patient experiences of a mobile health clinic



| Journal: | *BMJ Open* |
|---|---|
| Manuscript ID | bmjopen-2022-066674 |
| Article Type: | Original research |
| Date Submitted by the Author: | 15-Jul-2022 |





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| Keywords: | Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, PRIMARY CARE, QUALITATIVE RESEARCH |
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# "It's so simple!" Lessons from the margins: A qualitative study of patient experiences of a mobile health clinic

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**Keywords**: mobile health care clinics, qualitative research, under-served, homeless

**Word Count**: 6242

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**Abstract**

**Objective**: Our study explored the experiences of clients of HAMSMaRT (Hamilton Social Medicine Response Team), a mobile health service, in the context of their experiences of the overall healthcare system. **Design**: We conducted a reflexive thematic analysis. **Setting**: HAMSMaRT is a mobile health service in Hamilton, Ontario Canada. **Participants**: Fourteen clients of HAMSMaRT were interviewed. **Results**: Our findings represented five themes. Three themes served to be mechanisms through which HAMSMaRT was associated with better outcomes. These "mechanisms" included *people deserve care, from the margins to the centre*, and *improved and different access to the system*. **Conclusions**: With these three concepts enacted, the model of care works, represented by the theme *it works!*. The way in which participants compared their experiences of HAMSMaRT to the mainstream healthcare system insinuated how simple it is, represented by the theme *it's so simple*. Our findings offer guidance to the broader healthcare system for walking from the rhetoric to practice of person-centred care.

**Keywords**: mobile health care clinics, qualitative research, under-served, homeless

**Strengths and limitation of this study**

- Represents and centres the client perspectives of a mobile health service
- Authenticity, credibility, and trustworthiness of the data were upheld to foster quality of our approach
- Group of participants who were involved with one type of mobile health clinic interviewed
- Constitution and size of sample preclude an intersectionality approach

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## INTRODICTION

Mobile health clinics have been shown to be effective in meeting the health needs of (health) equity-deserving populations by providing services directly in patients' own environment, with the flexibility to adapt services to the needs of the patients these clinics serve.[1] Some of the advantages that mobile health services have been shown to provide include geographic/logistic convenience for patients who face barriers to accessing mainstream health care services, the ability to foster trusting patient-provider relationships, and the ability to better address the social determinants of patient health and connect patients to wider community resources.[1] Mobile health services have also been shown to decrease health care costs, by helping to avoid unnecessary emergency department visits and hospital admissions.[1,2]

Even in the setting of *universal* health care in Canada, provider-centred health services create physical and logistic barriers to access.[3] It has also been well documented that barriers to health care for patients who are deprived of housing and/or who use drugs are exacerbated by stigma, structural violence, and a lack of cultural safety in the healthcare setting, leading to poor health outcomes including inadequate withdrawal management, inadequate treatment of pain, early discharges, and avoidance of medical care altogether.[4-6] It has been suggested that mobile health services offer a particularly crucial supplement to other sources of health care for patients who are deprived of housing and who are not well served by the status quo model of medical care delivery.[3,7]

A review of published literature on the scope and impact of mobile health clinics in the United States,[1] and grey literature,[8,9] demonstrates that mounting evidence of the effectiveness of mobile health clinics is largely quantitative. Some scholars[1] have called for future research to explore the strengths of mobile health clinics versus traditional care models from the client perspective. In addition, research of mobile health clinics is scarce for people who are deprived of housing. One qualitative study in Toronto showed that mobile health programs can provide convenient, non-judgmental care for homeless patients who are underserved by the mainstream medical system.[3] Thus, the aim of this study is to explore client experiences of HAMSMaRT (Hamilton Social Medicine Response Team), a mobile, physician-led service, in the context of their access to and quality of care within the overall healthcare system. Our research question was, what is the patient experience of HAMSMaRT as part of their overall experience within the healthcare system?

## STUDY SETTING

The study reported here is part of a larger study which aimed to create an evaluation tool for mobile outreach clinics, via a clinician-centred Delphi consensus process and patient-generated quality of care indicators. Results of the larger study will be reported elsewhere.

### Broader local context

Our study took place in Hamilton Ontario, an urban setting with an overall population of 776,000 people. At the time of the data collection, a number of health care services in Hamilton (e.g., Shelter Health Network, Refuge Centre for Newcomer Health, North Hamilton and Urban Core Community Health Centres, etc.) were mandated to serve equity-deserving populations. These services, however, are almost exclusively provided in a fixed, office environment where patients must travel to the provider, at specified appointment or drop-in times, for necessary medical

care, while some clinics are co-located with existing social services (e.g., shelters, drop-ins). There are a handful of clinical outreach services which provide nursing or midwifery care, but few offer primary/physician care. The landscape has shifted marginally since and during COVID, but by and large, primary care for our study population is provided in a clinic setting.

**Description of HAMSMaRT+**

The Hamilton Social Medicine Response Team was founded in 2016 by two internal medicine physicians as a simple, ethical, intervention to support their patients in accessing much needed, but often not received, health care. The HAMSMaRT model was born of genuine listening and responding to patient concerns and desires about, and for, their own health and healthcare. HAMSMaRT is a mobile, interdisciplinary service that strives to provide care to individuals who otherwise have difficulty accessing care in the mainstream system, at a location where they are most comfortable. Patients, broadly speaking, are either unhoused/precariously housed, or unable to leave their homes primarily due to mobility difficulties. At the time of data collection, HAMSMaRT had a patient base of 200 individuals. HAMSMaRT works toward bridging the gap between the community and hospital services, establishing close relationships and formal partnerships with clinical programs and community organizations serving equity-deserving people in Hamilton.

## METHODS

We used a qualitative interpretive study design. We chose a qualitative study so that we could explore perspectives of the people who use HAMSMaRT and capture the nuances of the patient experience with HAMSMaRT. One-on-one semi-structured interviews were conducted. The interviews took place between April of 2018 to May of 2019.

**Patient and Public Involvement**

No patient or public involved in methodology development.

**Participants**

All participants were patients of HAMSMaRT, which meant they lived in Hamilton, Ontario and struggled to access care through conventional modes. Participants for this study also had to be at least 16 years of age and understand English enough to engage with the interviewer.

**Research team**

The research team consisted of 3 people. The team was a mix of clinicians and researchers involved with HAMSMaRT and working within addiction medicine. All authors endorsed a harm reduction approach to addiction and clinical care more broadly. At the time of the study, the third author was an infectious disease specialist with expertise in addiction medicine and low-barrier care for people who use drugs. He was a co-founder of HAMSMaRT. He was involved with the conception of the study, recruitment, and report writing. He also participated in data analysis (thematic refinement). The first author was a registered midwife completing her masters in Health Research Methods. She was involved with the conception of the study,

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+ Since the time of data collection in 2018-19, fuelled by the COVID pandemic, HAMSMaRT has undergone significant expansion and formalization of its programming. It continues to operate from its founding ethic of providing the care that people need where they need it. For more on HAMSMaRT's current programming, interdisciplinary model and organizational principles, please see hamsmart.ca.

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conducted most of the interviews, and was involved in data analysis at all stages and report writing. People accessing HAMSMaRT can have a distrust with healthcare providers and the healthcare system; however, she had experience working with people who used HAMSMaRT, thus had the knowledge and rapport to conduct the interviews. Also, her training in interviewing and qualitative methods has been grounded in sensitive topics. Since the time of the study, she has taken on a larger leadership role in HAMSMaRT. The second author was a research associate with over 15 years of research experience and seven years of research experience in primary care. They were brought onto the team during data analysis to guide the process. They also were involved in report writing. Two medical students were also involved in the project. Their role was to assist with data collection. They were not involved in analysis or report write-up. The first author was responsible for consistency between interviewers in terms of following the interview guide.

**Interview guide**

The interview questions and probes centred on the concept of quality of care, that is, what qualities of HAMSMaRT were characteristic of good health care. To contextualize HAMSMaRT within the broader (and mainstream) healthcare system, we also included questions about the quality of care in the mainstream healthcare system. To understand ways to improve HAMSMaRT, we included questions to explore any negative experiences and probed for ways to improve the service. The third author and a medical resident developed the interview guide. No substantial changes were made after the first interview, or at other times during data collection. See Table 1 for the interview guide.

**Table 1. Interview guide**

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1. How would you describe your experiences with HAMSMaRT so far?
    a. How did you first encounter the program?
    b. How do you think HamSMART's services could be improved?
        i. Was there a specific time when HamSMART didn't meet your needs?
    c. What is it about HamSMART that you feel would be good to apply in other similar programs?
2. Can you tell me about any experiences when you felt like you got good quality care?
    a. What changes would you like to see in the healthcare system to better serve your needs?
    b. How do you know when you've received good quality care? Some people say it's a feeling they get or it's their physical health that's improved – what is it for you?
3. Based on your experiences, what was a time when you received poor quality health care?
    a. How do you know when you've received poor quality care? Is it a feeling, a change in your physical health, or something else?
    b. Have there been times when you weren't treated well? If so, what happened that made you feel that way?
    c. Have you ever experienced stigma while getting care? If so, how did it affect the care you received?
    d. Why do you think you received poor care?
4. What barriers have you experienced in accessing health care?
    a. What was the effect of those barriers on your ability to get care?
    b. How could your access to health care have been improved?
5. In general, what qualities do you hope for in a doctor?
    a. How do you like to make decisions with your doctor?
    b. What are the most important things to you to have a good relationship with your doctor?
    c. What kind of relationship do you like to have with your doctor?
    d. What training do you think docs/HC providers are missing to provide better care?

**Procedure**

Upon university research ethics board approval (Hamilton-integrated Research Ethics Board Project #4500), participants were recruited using purposive sampling so as to gather in-depth information related to our research question.[10,11] The third author recruited potential participants by inviting them (face-to-face) to share their experience with HAMSMaRT so that the team could understand what was and was not working. Participants were clearly informed that deciding not to participate in the study would not impact their care from HAMSMaRT. Interviews were conducted in person, one-on-one, in the setting of the participant's choice including in hospital, in the participant's home or shelter or a coffee shop. The interviews were audio recorded. Interviews were conducted and it was deemed by this first author when the richness of the information was sufficient to answer the research question[12] thus ending recruitment. Participants were compensated for their time with a $50 gift card upon completion of the interview.

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## Data analysis

Audio recordings were intelligently and professionally transcribed. Pseudonyms were given to each participant and transcripts were de-identified. A reflexive thematic data analysis was employed.[13,14] We followed the six steps of thematic analysis. Specifically, we read and re-read the transcripts as well as re-listened to the audio-recordings to familiarize ourselves with the data. The first author generated initial codes through inductive coding grounded in the data and grouped codes together to make initial themes. During team meetings (between the first and second authors) we reviewed potential themes by checking them against the data. We did this for each candidate theme and also across themes so as to review the potential viability of the entire story in the data. In team meetings we also defined and named themes. This phase involved staying true to the data while engaging with concepts from practice and research in this population. It was during this discussion that one allusive theme (*it's so simple*) crystallized. Finally, we produced a report that included a final thematic map. The thematic map was refined throughout the process. For example, team discussion took place to reflect on if and how the themes related to one another within the data. This discussion led to *how* the final thematic looks and therefore represents the data and overall story. Data collection and analysis was concurrent.

The analysis was grounded in a pragmatic framework[15] thus, rigour is driven by the research question. Since we wanted to explore participants' experiences with HAMSMaRT within the context of their experiences with the mainstream healthcare system, we used an interpretive approach to analysis. Authenticity, credibility, and trustworthiness of the data were upheld to foster quality of our approach.[16, 17] We display direct quotations from participants in the results (authenticity). Participants who were served directly by HAMSMaRT comprised the sample so as to gather information about experiences of this model of care. Also, participants had experiences with the mainstream healthcare system (e.g., emergency departments, hospitals, primary and specialist care) which meant they were able to articulate perceived differences and similarities between both models of care. Being able to speak about both models of care was important to the research question (credibility). We also use thick descriptions to contextualize our sample and local setting (credibility). Finally, the initial theme development was discussed and challenged (trustworthiness) among the authors whereby the team's different clinical, community and research perspectives strengthened analysis[18] and led to the final thematic map.

## RESULTS

A total of 14 people participated. There were no dropouts or refusals to participate. Interviews lasted between 45 and 90 minutes. Sixty-four percent of participants were female, and the average age was 48 years at time of interview (range 25-69). Primary medical diagnoses included HIV, Hepatitis C, chronic obstructive pulmonary disease, congestive heart failure, diabetes, opioid use disorder and alcohol use disorder. Sixty-four percent reported active substance use. Most of these conditions were complicated and compounded by the patients' living conditions, broadly speaking, either of being housebound (35%) or unhoused/precariously housed (65%).

Participants drew on their experiences with HAMSMaRT and a broad range of experiences within the mainstream healthcare system. It was through a juxtaposition of HAMSMaRT experiences to experiences with the mainstream healthcare system that a total of five themes

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were developed. These themes included: *people deserve care*, *from the margins to the centre*, *improved and different access to the system*, *it works!* and *it's so simple*.

**Thematic map overview**

As shown in Figure 1, three themes described mechanisms through which HAMSMaRT was associated with higher patient satisfaction, engagement and ultimately better outcomes. These "mechanisms" included *people deserve care, from the margins to the centre*, and *improved and different access to the system*. How these mechanisms operate are important - *people deserve care* and *from the margins to the centre* are tethered to one another. They are foundational to HAMSMaRT; without them, the model of care falls down. Important here too is that the third mechanism (*improved and different access to the system*) cannot work in a vacuum; access can only be realized with the theme *people deserve care* tethered to the theme *from the margins to the centre*. When these three things work, it is associated with better patient-described outcomes (*it works!*). These mechanisms were crystallized when HAMSMaRT experiences were juxtaposed to experiences of the mainstream healthcare system. In many cases these mechanisms were absent in the mainstream healthcare system leading to poorer patient described outcomes, and ultimately something that does not work. A fifth theme, *it's so simple*, operates as the thematic map frame, containing the mechanisms that lead to better outcomes. The note to the thematic map represents how simple this model is (and can be). The final thematic map was also hand-drawn to symbolize the theme, *it's so simple*.

**People deserve care**

This theme represents the basic notion that patients of the healthcare system are human and deserving of dignity and respect by virtue of that fact alone. The theme *people deserve care* signals a recognition on the part of its patients of this founding ethic of HAMSMaRT.

*People deserve care* came to life in contradistinction to participant's experiences of the mainstream healthcare system that left them feeling they "did this to themselves" and thus did not deserve help and that care providers had more important people to serve. These interactions were lathered with judgment, blame, and insensitivity. One participant:

> The things that [the healthcare provider] had said to me, he said that I had done this to myself because of the choices that I've made [crying] in my life, that I was a horrible person, and then [my partner] just told him that he could basically go to hell, and she took me out and we left [crying] (Gail)

Participants repeatedly, reliably, and in great detail described dehumanizing and harmful exchanges that deterred them from seeking healthcare. Because of their treatment at the hands of the healthcare system, patients we interviewed both recognized and struggled to remember that they were 'more than a junkie' and not 'a child' or a number:

> Because it does make me feel worthless to have to go somewhere where I know I'm not going to be welcome for one, treated properly for another, and even care if I live or die sometimes I feel. You know? Sometimes I feel that there are some people in healthcare that think a dead junkie is a better junkie. You know? I really feel that there are people that feel that way. And that's sad. We are all human beings and we all have value.

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> (Gabriel)

Another participant talked about prioritization by social status in mainstream healthcare provision, insinuating that some people are more important than others:

> But I find in the general healthcare system, they classify people. First off, and they really classify you if you have more than one or two strikes that are different, i.e. if you are on ODSP [Ontario Disability Support Program], addicted to opiates, a bit of an alcoholic, things like that, they are saying oh well, [...]let's get to the important people first and then we will get to him. (Demarcus)

Conversely, interactions between HAMSMaRT and participants were characterized by feelings of being treated as a human being with (equal) value. They described being engaged with respect, dignity, honesty, and genuine care. One participant described their experience with HAMSMaRT:

> There's not another doctor that I've ever met that will go to the lengths that HAMSMaRT does to try to save the people at the bottom of the rungs in society. And there are some people in the bottom of the rungs that have real value, that have real things to offer society. And that's what most people don't realize. We're not all pieces of crap. We're not all looking to hurt people and take from society. We ended up there through one situation or another, you know? We all have our own stories to tell about how we ended up there. But I have met so many addicts in my experience that have bigger hearts than anybody I've ever met. And have more to offer society than a lot of people. If only someone showed them that they had value. If only someone cared for them, because they're dying out there. People who, if they really felt that somebody cared, that somebody was there for them, you know, it would make such a difference. And I think that's where HAMSMaRT comes in. (Gabriel)

Patients repeatedly described that working with providers who saw them as deserving affirmed or unearthed a belief in themselves that provided them with the will to keep going and to try to heal:

> I finally started advocating for myself. I was tired. I lost everything. And then I didn't see anybody offer me a way out. So I just thought more of the status quo. And so when you have people, like those doctors, [the HAMSMaRT doctor], I came out of the hospital the last time feeling like I have a plan with hope again. (Greta)

This humanizing approach to care, explicitly driven by the ethic that *people deserve care* was described as a way in which the patient was taken from the margins to the centre of their own care.

**From the margins to the centre**

This theme represents the participants' transformative experience of moving from the mainstream system's heretofore unrealized tenet of patient-centred care into a concrete practice of being the focus of their own care. This theme represents qualities of patient-centred and patient-focused care that are baked into HAMSMaRT, and tethered to the previous theme (*people deserve care*).

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While patient-centred care was recognized by participants as a rhetorical hallmark of the Ontario and Canadian mainstream healthcare systems writ large, it rarely characterized their experiences when accessing care. Over and over, participants described a throughline of their experiences as being judged, ignored, disregarded, discounted, excluded and silenced, in both hospital- and office-based care settings. Rowan summarized their experience:

> They just think that you can't do things. But the thing is that I can do a lot. I can't do everything. But I was in control of my own life and then other people were treating me like a child. And that's the way I felt at the doctors. I was being treated like a child. (Rowan)

Participants, often quite generously, attributed this decentering and patronizing behaviour on the part of providers to several organizational issues in the healthcare system, including heavy patient loads and provider fatigue. They primarily experienced it however, as a powerplay that elevated the physician at their own expense. Greta said:

> And I lost all trust in doctors. I lost all hope that I had. Not because they couldn't be good doctors, but it's…I'm the hero in this story too. You know what I mean? But they played God. (Greta)

Participants repeatedly asserted that healthcare providers didn't have a monopoly on health knowledge:

> Just because we don't have a medical license, doesn't mean we don't know what's going on with our own bodies. We're the first person who knows what's going on with us. (Freya)

Centering the patient meant dissolving the well ingrained provider-patient (knowledge) hierarchy; recognizing and acting on the intelligence and experiential expertise that the patient brought to the table when making decisions about care. When this expertise is listened to, appreciated and worked with, shared decision making is realized. True to power-sharing is the notion that the provider and patient are equal in the relationship:

> [The HAMSMaRT doctor] doesn't act like he's saving me, and that's a huge difference, because I get to be a person and I get to be an expert on my own care. And so we can work together. And to me that is what I lost with everybody else. (Greta)

This kind of power sharing depends on provider affirmation of patient autonomy. Genuine respect for patient autonomy was experienced by patients as being listened to and believed. Believing and centering patients as experts in their own health experiences led to a bi-directional cycle of truth and trust previously unenjoyed. This power sharing enhanced the provider's ability to help and the patient's ability to heal. Greta continued:

> If I didn't have this…because as I said, I had lost all hope, all belief. I thought there wasn't any hope. So when I finally had people working for me, then it felt like…somebody is working with me and I will work with them. Yeah! We have hope now that I can get out of this mess. And I can have a future. (Greta)

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These mutually reinforcing orientations to patient care of deserving and centering allowed for as new and different access to care systems to which patients were at best, reticent about and at worst, deliberately avoiding.

**Improved and different access to the system**

This theme describes the well-known ways in which mobile, flexible, on call, health services are necessary to increase access to care. Importantly, however, the theme also elucidates how the HAMSMaRT model provides *improved and different* access to the wider healthcare system.

For all of the participants, logistical barriers to accessing care in the mainstream system were a major roadblock to improving their health. Patients described inaccessible offices, inflexible hours, difficulties navigating the system and complex and competing priorities in a provider-centred system that refused to recognize or address all of the barriers it erected:

> And I tried explaining it to them over the phone. I said 'I can't get out. I'm housebound.' 'Oh well, you have to come down and get these.' And I said, 'you want me to come all the way down just to pick up papers? It's not to see a doctor?' And she said 'yeah.' (Rowan)

Unsurprisingly, participants were extremely appreciative of HAMSMaRT's outreach model, which included ready access to physician support by phone, home/out of office visits and flexible scheduling. These "above and beyond" measures were viewed as a tangible enactment of the two previous themes:

> It helps because like I already said, it makes you feel important. It makes you feel special for one. So right away, you feel part of and willing to go and do whatever is required to go that extra mile to help these people, because they are coming all the way to my house. I'll certainly do what I can to help. If they're going to help me like this, then I'll help them help me. (Charlie)

Improved and different access, sometimes translated into less unnecessary use of health systems. Patients described the ways in which access to HAMSMaRT services meant they could stay out of the resource intensive emergency room, where previously (though they didn't want to) they had no choice but to go for care:

> It's incredible to have a doctor care for you and you can just text him and he's like OK, he calls the pharmacy. Or OK, I've got this going for you. Like [what happens when you start to develop an infection] Friday at 5 o'clock? Like go to the ER. And then you go through the whole process all over again. But if you have a doctor on hand like [the HAMSMaRT doctor], there's so many times when I've just called him and he's like, OK, I'm putting in something, a [prescription] or something like that. He's saved me so many times from having to go to the ER. (Nola)

Just as patients were moved by HAMSMaRT providers' decisions not to leverage their power against them, they were compelled by the way HAMSMaRT providers wielded their power *for* them; and sometimes miffed that it worked! In several instances, participants described scenarios

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that took the HAMSMaRT doctor's power as physician to communicate the patient's expertise, which led to care access:

> And all I called was [the HAMSMaRT doctor] and he called the [emergency room] doctor and boom I was in. It was…in a way it was frustrating, but in a way I was so relieved, you know? It was like a double-edged sword. It was like you fucking bastards. Pardon my language. But really that's what I thought. You bastards. Like this is my third visit in a week and all it took was one call from [the HAMSMaRT doctor]. OK, this patient has this, this, this, which I told them I had, which I told them I thought I had. And he repeated every single thing I said, probably to the tee and they listened to him and not to me. You know what I mean? That's not fair, you know? And I even said to him, what did you say to them? And he said, 'pretty much what you said.' He's like, 'yeah I know, it's OK. One problem at a time Freya', that's what he said, 'one problem at a time.' (Freya)

Importantly, this improved and different access also meant that patients who had previously struggled to stay in the hospital (for the maltreatment they had become so accustomed to) now could. This participant shared how their involvement with HAMSMaRT changed their access to the mainstream healthcare system:

> In hospitals, I've always been treated differently than other patients because I have an addiction. And I don't think it's fair that I should be left to suffer in pain. I have pain issues and significant pain issues that are well documented and all verified through imaging and things like that. And since I've been dealing with HAMSMaRT [...], when I'm in the hospital, I feel like I'm treated differently now, right? Because [the HAMSMaRT doctor] always has some involvement in my care [...]. So when it comes to my pain issues and things like that, they try their best to deal with it. And I've never felt like any healthcare institution has ever tried their best on my behalf. And I feel that now. And I truly believe it's because of the involvement of HAMSMaRT. (Gabriel)

Finally, some participants described a renewed trust in possibilities of healthcare, stemming from the advocacy efforts of the HAMSMaRT:

> Well working with [the HAMSMaRT doctor] made me come to terms of learning to trust doctors more than what I did, because I never really had any doctors that I wanted to see. If I was sick I dealt with it. And then something like this happens. So for that year that I had the infection, it was like I'm going to conquer this, I'm going to kill it. No two ways about it. Nobody is taking my leg or whatever. And then it so happens that the inevitable happens. Maybe I should listen to doctors a lot more. For me that's my learning experience. Now I kind of have to trust doctors and nurses more. If they say well maybe you should do this, then that's what I'm going to do. (Marlow)

These tangible and behind the scenes strategies alike were described by participants as helping them access care, leading to improvement in health, i.e. it worked!.

**It works!**

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For many centred in the healthcare system, the answer to the question of "how do you know you got good care?" takes for granted that, to the extent possible, the healthcare improved the person's health. Participant responses to this question were simple, humble and profound. Their responses spoke to how, when the three themes are brought to life, the model of care (i.e., HAMSMaRT) works. Startlingly, participants described having health improvements as the way they knew they were getting good care:

> Just seeing results, seeing the results of me getting better is proof in itself that I know that what they are doing is working. (Isla)

Freya also felt "better" since being involved with HAMSMaRT. Demarcus told us:

> "There is no doubt. 100%. Because it was constant care. Difference in between waiting until I got sick and then going, then acting or reacting to that. As opposed to acting and the outcome being instead gratifying. Yeah. I felt much more at ease knowing that I could talk to him and be pointed in the right direction." (Demarcus)

Again, participants drew conclusions about their success with HAMSMaRT by drawing on, and comparing to, their experiences with the provider-centred health care system:

> And you know, I had lost 100lbs since [major life event]. Since I've actually been getting what I think is quality healthcare, I've gained 45 of that back. Even though I was still using, I've had people say wow you look better than you've looked since [that major life event]. And I even feel it. I feel better. I look better. I'm more engaged in life. I care more about my life now. So those are the things that I think prove to me that my healthcare is better now than it was before. (Gabriel)

Participants spoke about hope and engagement in life as outcomes of their involvement with HAMSMaRT. Rowan described the profound impact of the simplicity of the HAMSMaRT approach:

> And [the HAMSMaRT doctor] came down and talked to me about stuff, and I [...] actually had given up on living. And he sat and talked to me, and said don't give up. Let's try this, we'll do this, we'll work on this. And he was giving me all these other ideas where when my family doctor dropped me and my liver doctor wasn't doing her job properly, I had just given up. I just wanted to curl up and die. And he got me back into wanting to fight to live. So that's why I'm still here. (Rowan)

Some participants expressed optimism that HAMSMaRT could lead to change in the system through replication and scaling up:

> It's amazing. You guys are doing something…I don't know what the word is for it. Like um…ground changing, or groundbreaking. Really. If more people can have this, it's going to change the way they feel about doctors and medicine. You guys really helped me. (Freya)

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There was even a glimpse of restored faith in the possibility of healthcare that heals - “I actually believe now in care [...] and I just love not being sick anymore.” (Isla)

In an increasingly technocratic, regimented and strained healthcare system it's impossible to miss the simplicity of what patients have here described as setting their experiences apart from those of the larger healthcare system.

**It’s so simple**

There was a tone to the interviews that speaks to the simplicity of what participants viewed as requisite to a healing process. One keen and insightful participant summed it up very succinctly:

> It really is [that simple] and I don’t see why it seems so hard sometimes in the hospitals. Just treat a person as a person. That’s the biggest thing that could be adopted from HAMSMaRT to the healthcare system overall. (Gabriel)

Isla brought this theme of simplicity into stark reveal describing her perception of a shift in her care since working with HAMSMaRT. She said that it was the likelihood that she wouldn’t be treated “like shit” that enabled her to seek the care she needed. It doesn’t get much simpler than that.

For our team, many of the strategies participants described are things we already know improve access and quality of care. One participant with extensive experience as an inpatient described a small interaction that stood out from all her time spent in hospital:

> I moved to the B wing after the E wing, and the nurse came in and I expected something. So I was like, oh, did you need me to sign something or did you need something? She goes, no I’m just coming to say hi and tell you that I’m your nurse and my name is so-and-so. And she left. And I was like holy crap. That was like…that made me feel so good and it was 2 seconds…I think that’s what makes it so frustrating, is that there is not much to it. (Nola)

Here a two second interaction made the difference. Simple.

## DISCUSSION

Our study explored the experiences of people involved in HAMSMaRT in the context of their access to and quality of care within the overall healthcare system. Our findings provide evidence that HAMSMaRT brings to life three simple mechanisms: beginning with the principles that people deserve care and should be at the centre of it, leading to improved and different access to the system. When these three things are enacted, the model of care (HAMSMaRT) works. The profundity and simplicity of what patients described as quality care as realized through HAMSMaRT, and how elusive it was in the mainstream healthcare system, should give us all pause as health providers.

Our findings corroborate those of Wen and colleagues'[19] exploration of the dehumanization of people experiencing homeless by the healthcare system. Wen and colleagues frame patient

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experiences as welcoming versus unwelcoming, noting that the latter's stigmatizing ethic, like in our findings of patient experiences in the mainstream health system, leads to system aversion.

Our findings also contribute to the growing evidence that mobile health clinics are effective in improving health outcomes of equity deserving people.[1,8,9] They further contribute to the small body of qualitative evidence for the effectiveness of mobile health clinics that serve people who are deprived of housing.[3] While Whelan and colleagues[3] explore why people use a mobile health clinic (accessing basic necessities, convenience, friendly atmosphere), our findings probe *what* it is about the model that works. Our findings describe the nuances of quality care and help to elucidate the what and the how behind the quantitative evidence of the effectiveness of mobile health clinics. In essence, our findings flesh out and affirm Wen et al.'s[19] suggestion that "the provision of effective care may be tied to the ability to create a welcoming environment."

Research about care of equity deserving populations primarily directs its gaze at either the patients of, or providers to, the population in question. The sizable body of work around patient barriers to and experiences of health care is congruent with our findings that stigma and discrimination are major deterrents to care and barriers to improved health outcomes.[20-22] There is a smaller body of work on the experiences of providers caring for equity deserving populations which enumerates the difficulties of providing welcoming, high-quality care within the confines of the provider-centred health system; these difficulties include providing humanized service in a stigmatizing health care milieu.[23-26] There are some efforts described in the literature to develop methods for combating the deterring stigmatizing nature of health systems[27-29]; however, there is little work done to excavate what undergirds such stigmatizing care delivery. Our findings and the existing literature demonstrate that there is a disjoint between the widely adopted rhetoric of patient-centred care and the actual practice by a critical mass of providers. Exploring this, perhaps through the perceptions and experiences of providers in the mainstream healthcare system, is an area of study rife with transformational potential.

A few caveats should be acknowledged. Our findings come from a group of participants who were involved with one type of mobile health clinic. Although the goal of qualitative research is not to generalize and we provide enough rich description to contextualize both the sample and HAMSMaRT for transferability of our findings to similar contexts, we cannot ignore that there may be contextual factors that make transferability difficult. These factors may include population-level characteristics (e.g., racial or ethnic background, language) or system-wide policies of funding structures. Additionally, the constitution and size of our sample precluded us taking intersectional approach to understanding the layered stigma (and multi-stigma), discrimination and racism meted out by the health system. Also missing is the healthcare provider perspective; why might this model work for patients from the viewpoint of the provider?

We share these findings, lauding the HAMSMaRT model, with humility and in deference to the brilliance of the patients with whom we work. While we hope that the insights shared by participants will be taken up by others striving to provide better care, we also commit to implementing these findings in our own growing and changing organization. Since the time of data collection in 2018 we continue to bridge the gap between the community and hospital care. We have secured semi-stable funding, expanded and consolidated our services through a formal

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partnership with a user-led harm reduction group in the city, established a multi-site safer supply program for people using opioids, incorporated psychiatry and primary care into our clinical model and expanded our organizational team. We strive to extrapolate the lessons learned from these descriptions of the one-on-one patient interactions to our own HAMSMaRT "health system"; we take our lead as a healthcare organization from our patients and the community to which we all belong. All of our work begins from the principle that people deserve care that centres them, which allows us to provide improved and different access to healthcare - it works and it is that simple.

**CONTRIBUTORSHIP STATEMENT**

First and third authors were responsible for research idea conception and recruitment. First author was responsible data collection oversight. First and second authors were responsible for data analysis. All authors contributed to report writing and knowledge translation.

**ACKNOWLEDGEMENTS**

The authors wish to thank and acknowledge, first and foremost the HAMSMaRT patients and participants who have shared their lives and experiences with us as providers and researchers. We hope that this paper does your ideas and insights justice. We would also like to thank Dr. Sheiry Dhillon for her input into the early phases of the overall project to develop an evaluation tool for mobile outreach clinics. Thank you to Jane Tooley and Jesse Bauman for conducting some of the interviews in this project. Thank you also to Dr. Nicole Buchanan for her contributions to the background research for the project.

**COMPETEING INTERESTS**

We have no competing interests or conflicts of interests to declare.

**FUNDING STATEMENT**

This work was not funded.

**DATA SHARING STATEMENT**

Deidentified data will be shared upon responsible request by contacting the corresponding author.

**ETHICS APPROVAL**

Ethics approval for this project was received through the Hamilton-integrated Research Ethics Board (Project #4500).

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## REFERENCES

1 Yu SW, Hill C, Ricks ML, Bennet J, Oriol NE. The scope and impact of mobile health clinics in the United States: a literature review. *Int J for Equity Health* 2017;16(1):1-12. https://doi.org/10.1186/s12939-017-0671-2

2 Oriol NE, Cote PJ, Vavasis AP, Bennet J, DeLorenzo D, Blanc P, Kohane I. Calculating the return on investment of mobile healthcare. *BMC Med* 2009;7(1):1-6.

3 Whelan C, Chambers C, Chan M, Thomas S, Ramos G, Hwang SW. Why do homeless people use a mobile health unit in a country with universal health care?. *J Prim Care Community Health* 2010;1(2):78-82. https://doi.org/10.1177/2150131910372233

4 Giesbrecht M, Stajduhar KI, Mollison A, Pauly B, Reimer-Kirkham S, McNeil R, Wallace B, Dosani N, Rose C. Hospitals, clinics, and palliative care units: Place-based experiences of formal healthcare settings by people experiencing structural vulnerability at the end-of-life. *Health Place* 2018;53:43-51. https://doi.org/10.1016/j.healthplace.2018.06.005

5 Harris M. Normalised pain and severe health care delay among people who inject drugs in London: Adapting cultural safety principles to promote care. *Soc Sci Med* 2020;260:113183. https://doi.org/10.1016/j.socscimed.2020.113183

6 McNeil R, Small W, Wood E, Kerr T. Hospitals as a 'risk environment': an ethno-epidemiological study of voluntary and involuntary discharge from hospital against medical advice among people who inject drugs. *Soc Sci Med* 2014;105:59-66. https://doi.org/10.1016/j.socscimed.2014.01.010

7 Shortt SE, Hwang S, Stuart H, Bedore M, Zurba N, Darling M. Delivering primary care to homeless persons: a policy analysis approach to evaluating the options. *Healthc Policy* 2008;4(1):108.

8 Egwu, E. Mobile health clinic as a medium for reducing health disparities in underserved populations. Dissertation Georgia State University 2019. https://scholarworks.gsu.edu/nursing_dnpprojects/15

9 Jimenez A. The use of mobile healthcare clinics to expand access to underserved populations: a rapid review. Undergraduate honors thesis Central Washington University 2019 https://digitalcommons.cwu.edu/undergrad_hontheses/14

10 Liamputtong, P. Qualitative Research Methods, 4th Ed. Melbourne: Oxford University Press 2013.

11 Patton MQ. Qualitative Research and Evaluation Methods, 3rd Ed. Thousand Oaks, CA: Sage 2002.

12 Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qual Res Sport Exer Health* 2019; 13:1-16.

13 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psych* 2006;*3:* 77-101. https://doi.org/10.1191/1478088706qp063oa

14 Braun, V, Clarke, V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exer Health* 2019;*11*(4): 589-597.

15 Morgan DL. Pragmatism as a paradigm for social research. *Qual Inq* 2014;20:1045-1053. https://doi.org/10.1177/1077800413513733

16 Lincoln YS, Guba EG. But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New Dir Eval* 1989; 30:73-84.

17 Tracy SJ. Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. *Qual Inq* 2010;16(10): 837-851. https://doi.org/10.1177/1077800410383121

18 Patton MQ. Enhancing the quality and credibility of qualitative analysis. *Health Serv Res* 1999;34:1189-1208.

19 Wen CK, Hudak, PL, and Hwang SW. Homeless people's perceptions of welcomeness and unwelcomeness in healthcare encounters. *J Gen Intern Med* 2007;22:1011-1017.

20 Kalich A, Heinemann L, Ghahari SA. Scoping review of immigrant experience of health care access barriers in Canada. *J Immigr Minor Health* 2016;18:697-709. https://doi.org/10.1007/s10903-015-0237-6

21 Ramsay N, Hossain R, Moore M, Milo M, Brown A. Health care while homeless: barriers, facilitators, and the lived experiences of homeless individuals accessing health care in a Canadian regional municipality. *Qual Health Res* 2019;29(13):1839-1849. https://doi.org/10.1177/1049732319829434

22 Monchalin, R, Smylie J, Nowgesic E. "I Guess I Shouldn't Come Back Here":racism and discrimination as a barrier to accessing health and social services for urban Métis women in Toronto, Canada. *J Racial Ethn Health Disparities* 2019;7(2)251-261. https://doi.org/10.1007/s40615-019-00653-1

23 McKeary M, Newbold, B. Barriers to care: the challenges for Canadian refugees and their health care providers. *J Refug Stud* 2010;23(4):523-545. https://doi.org/10.1093/jrs/feq038

24 Loignon C, Hudon C, Goulet É, Boyer S, De Laat M, Fournier N, Grabovschi C, Bush P. Perceived barriers to healthcare for persons living in poverty in Quebec, Canada: the EQUIhealThY project. *Int J Equity Health* 2015;14(1):1-11. https://doi.org/10.1186/s12939-015-0135-5



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25 Campbell DJ, O'Neill BG, Gibson K, Thurston WE. Primary healthcare needs and barriers to care among Calgary's homeless populations. *BMC Fam Pract* 2015;16:1-10. https://doi.org/10.1186/s12875-015-0361-3

26 Darling EK, MacDonald T, Nussey L, Murray-Davis B, Vanstone M. Making midwifery services accessible to people of low SES: a qualitative descriptive study of the barriers faced by midwives in Ontario. *Can J Midwif Res Pr* 2020;19(2): 1-13.

27 Stuart H, Chen SP, Christie R, Dobson K, Kirsh B, Knaak S, Koller M, Krupa T, Lauria-Horner B, Luong D, Modgill G. Opening minds in Canada: targeting change. *Can J Psychiatry* 2014;59(suppl):13-18. https://doi.org/10.1177/070674371405901S05

28 Stuart H. Managing the stigma of opioid use. *Healthcare Management Forum* 2019;32(2):78-83. https://doi.org/10.1177/0840470418798658

29 Ungar T, Knaak S, Szeto AC. Theoretical and practical considerations for combating mental illness stigma in health care. *Community Ment Health J* 2016;52(3):262-71. https://doi.org/10.1007/s10597-015-9910-4

**FIGURE LEGEND**

Thematic map

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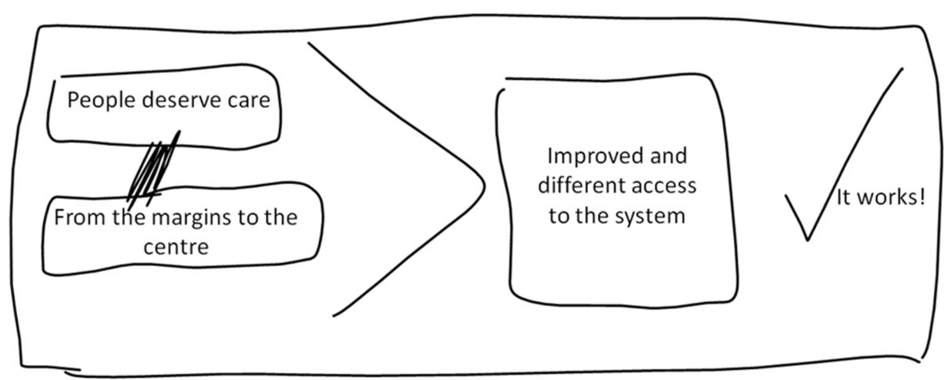


*Note.* It's so simple

Thematic map

338x190mm (96 x 96 DPI)

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**Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist**

| No. Item | Guide questions/description | Reported on Page # |
|---|---|---|
| **Domain 1: Research team and reflexivity** | | |
| *Personal Characteristics* | | |
| 1. Inter viewer/facilitator | Which author/s conducted the interview or focus group? | 5 |
| 2. Credentials | What were the researcher's credentials? E.g. PhD, MD | 5 |
| 3. Occupation | What was their occupation at the time of the study? | 5 |
| 4. Gender | Was the researcher male or female? | 5 |
| 5. Experience and training | What experience or training did the researcher have? | 5 |
| *Relationship with participants* | | |
| 6. Relationship established | Was a relationship established prior to study commencement? | 5-6 |
| 7. Participant knowledge of the interviewer | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research | 6 |
| 8. Interviewer characteristics | What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | 5 |
| **Domain 2: study design** | | |
| *Theoretical framework* | | |
| 9. Methodological orientation and Theory | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | 7 |
| *Participant selection* | | |
| 10. Sampling | How were participants selected? e.g. purposive, convenience, consecutive, snowball | 6 |
| 11. Method of approach | How were participants approached? e.g. face-to-face, telephone, mail, email | 6 |
| 12. Sample size | How many participants were in the study? | 7 |
| 13. Non-participation | How many people refused to participate or dropped out? Reasons? | 7 |
| *Setting* | | |
| 14. Setting of data collection | Where was the data collected? e.g. home, clinic, workplace | 6 |
| 15. Presence of non-participants | Was anyone else present besides the participants and researchers? | 6 |

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| 16. Description of sample | What are the important characteristics of the sample? e.g. demographic data, date | 7-8 |
|---|---|---|
| *Data collection* | | |
| 17. Interview guide | Were questions, prompts, guides provided by the authors? Was it pilot tested? | 5 |
| 18. Repeat interviews | Were repeat interviews carried out? If yes, how many? | No, no follow-up was deemed necessary |
| 19. Audio/visual recording | Did the research use audio or visual recording to collect the data? | 6 |
| 20. Field notes | Were field notes made during and/or after the interview or focus group? | No, we did not use this strategy to foster rigor, but used others |
| 21. Duration | What was the duration of the inter views or focus group? | 7 |
| 22. Data saturation | Was data saturation discussed? | 6-7 |
| 23. Transcripts returned | Were transcripts returned to participants for comment and/or correction? | No, we did not use this strategy to foster rigor, but used others. |
| **Domain 3: analysis and findings** | | |
| *Data analysis* | | |
| 24. Number of data coders | How many data coders coded the data? | 7 |
| 25. Description of the coding tree | Did authors provide a description of the coding tree? | 8 |
| 26. Derivation of themes | Were themes identified in advance or derived from the data? | 7 |
| 27. Software | What software, if applicable, was used to manage the data? | Not applicable |
| 28. Participant checking | Did participants provide feedback on the findings? | No, we did not use this strategy to foster rigor, but used others. |
| *Reporting* | | |
| 29. Quotations presented | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number | 9-16 |
| 30. Data and findings consistent | Was there consistency between the data presented and the findings? | 9-16 |
| 31. Clarity of major themes | Were major themes clearly presented in the findings? | 9-16 |
| 32. Clarity of minor themes | Is there a description of diverse cases or discussion of minor themes? | Not applicable; did not emerge in our analysis |

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# "It's so simple!" Lessons from the margins: A qualitative study of patient experiences of a mobile health clinic in Hamilton, Ontario, Canada

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|---|---|
| Journal: | *BMJ Open* |
| Manuscript ID | bmjopen-2022-066674.R1 |
| Article Type: | Original research |
| Date Submitted by the Author: | 25-Nov-2022 |
| Complete List of Authors: | Nussey, Lisa; McMaster University, Midwifery Research Centre<br>Lamarche, Larkin; York University, School of Kinesiology & Health Science<br>O'Shea, Tim; McMaster University, Department of Medicine |
| <b>Primary Subject Heading</b>: | Patient-centred medicine |
| Secondary Subject Heading: | Qualitative research |
| Keywords: | Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, PRIMARY CARE, QUALITATIVE RESEARCH |
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"It's so simple!" Lessons from the margins: A qualitative study of patient experiences of a mobile health clinic in Hamilton, Ontario, Canada

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**Keywords**: mobile health care clinics, qualitative research, under-served, homeless, people deprived of housing, patient-centred care

**Word Count**: 6100

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**Abstract**

**Objective**: Our study explored the experiences of clients of HAMSMaRT (Hamilton Social Medicine Response Team), a mobile health service, in the context of their experiences of the overall healthcare system. **Design**: We conducted a qualitative study with reflexive thematic analysis. **Setting**: HAMSMaRT is a mobile health service in Hamilton, Ontario Canada 'providing primary care, internal medicine and infectious diseases services. **Participants**: Eligible participants were clients of HAMSMaRT who could understand English to do the interview and at least 16 years of age. Fourteen clients of HAMSMaRT were interviewed. **Results**: Our findings represented five themes. When the themes of *people deserve care, from the margins to the centre*, and *improved and different access to the system* are enacted, the model of care works, represented by the theme *it works!*. The way in which participants compared their experiences of HAMSMaRT to the mainstream healthcare system insinuated how simple it is, represented by the theme *it's so simple*. **Conclusions**: Our findings offer guidance to the broader healthcare system for walking from the rhetoric to practice of person-centred care.

**Keywords**: mobile health care clinics, qualitative research, under-served, homeless, people deprived of housing, patient-centred care

**Strengths and limitation of this study**

- Adds to the small body of existing health service literature that represents and centres the client perspectives of a mobile health service
- Authenticity, credibility, and trustworthiness of the data were upheld to foster quality of our approach
- Group of participants who were involved with one type of mobile health clinic interviewed
- Constitution and size of sample preclude an intersectionality approach

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## INTRODICTION

Despite a model of *universal* health care in Canada, provider-centred health services create physical and logistic barriers to access.[1] It has also been well documented that barriers to health care for patients who are deprived of housing and/or who use drugs are exacerbated by stigma, structural violence, and a lack of cultural safety in the healthcare setting, leading to poor health outcomes including inadequate withdrawal management, inadequate treatment of pain, pre-mature discharges, and avoidance of medical care altogether.[2-4]

Mobile health services offer a particularly crucial supplement to other sources of health care for patients who are deprived of housing and who are not well served by the status quo model of medical care delivery.[1,5] They have been shown to be effective in meeting the health needs of (health) equity-deserving populations by providing services directly in patients' own environment, decreasing geographic/logistic barriers to accessing mainstream health care services. Additionally, mobile services have been shown to foster trusting patient-provider relationships, and the ability to better address the social determinants of health through connecting patients to wider community resources.[6] Mobile health services have also been shown to decrease health care costs, by helping to avoid unnecessary emergency department visits and hospital admissions.[6,7]

A review of published literature on the scope and impact of mobile health clinics in the United States,[6] and grey literature,[8,9] demonstrates that mounting evidence of the effectiveness of mobile health clinics is largely quantitative. Some scholars[6] have called for future research to explore the strengths of mobile health clinics versus traditional care models from the client perspective. In addition, research of mobile health clinics is scarce for people who are deprived of housing. One qualitative study in Toronto showed that mobile health programs can provide convenient, non-judgmental care for homeless patients who are poorly served by the mainstream medical system.[1] Thus, the aim of this study is to explore client experiences of HAMSMaRT (Hamilton Social Medicine Response Team), a mobile, physician-led service, in the context of their access to and quality of care within the overall healthcare system. Our research question was, what is the patient experience of HAMSMaRT as part of their overall experience within the healthcare system?

## STUDY SETTING

The study reported here is part of a larger study which aimed to create an evaluation tool for mobile outreach clinics, via a clinician-centred Delphi consensus process and patient-generated quality of care indicators. Results of the larger study will be reported elsewhere.

### Broader local context

Our study took place in Hamilton Ontario, an urban setting with an overall population of 776,000 people. At the time of the data collection, a number of health care services in Hamilton (e.g., Shelter Health Network, Refuge Centre for Newcomer Health, North Hamilton and Urban Core Community Health Centres, etc.) were mandated to serve equity-deserving populations. These services, however, are almost exclusively provided in a fixed, office environment where patients must travel to the provider, at specified appointment or drop-in times, for necessary medical care, while some clinics are co-located with existing social services (e.g., shelters, drop-ins). There are a handful of clinical outreach services which provide nursing or midwifery care, but

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few offer primary/physician care. The landscape has shifted marginally since and during COVID, but by and large, primary care for our study population is provided in a clinic setting.

**Description of HAMSMaRT+**

The Hamilton Social Medicine Response Team was founded in 2016 by two internal medicine physicians as a simple, ethical, intervention to support their patients in accessing much needed, but often not received, health care. The HAMSMaRT model was born of genuine listening and responding to patient concerns and desires about, and for, their own health and healthcare. HAMSMaRT is a mobile, interdisciplinary service that strives to provide care to individuals who otherwise have difficulty accessing care in the mainstream system, at a location where they are most comfortable. Patients, broadly speaking, are deprived of housing and are either unhoused/precariously housed, or unable to leave their homes primarily due to mobility difficulties. At the time of data collection, HAMSMaRT had a patient base of 200 individuals. HAMSMaRT works toward bridging the gap between the community and hospital services, establishing close relationships and formal partnerships with clinical programs and community organizations serving equity-deserving people in Hamilton.

## METHODS

We used a qualitative study design. We chose a qualitative study so that we could explore perspectives of the people who use HAMSMaRT and capture the nuances of the patient experience with HAMSMaRT. One-on-one semi-structured interviews were conducted. The interviews took place between April of 2018 to May of 2019.

**Patient and Public Involvement**

No patient or public involved in methodology development.

**Participants**

All participants were patients of HAMSMaRT, which meant they lived in Hamilton, Ontario and struggled to access care through conventional modes. Participants for this study also had to be at least 16 years of age and understand English enough to engage with the interviewer. Participants were purposefully sampled[10,11] by the third author from his patient roster.

**Research team**

The research team consisted of 3 people. The team was a mix of clinicians and researchers involved with HAMSMaRT and working within addiction medicine. All authors endorsed a harm reduction approach to addiction and clinical care more broadly. At the time of the study, the third author was an infectious disease specialist with expertise in addiction medicine and low-barrier care for people who use drugs. He was a co-founder of HAMSMaRT. The first author was a registered midwife completing her masters in Health Research Methods. People accessing HAMSMaRT can have a distrust with healthcare providers and the healthcare system; however, she had experience working with people who used HAMSMaRT, thus had the knowledge and rapport to conduct the interviews. Also, her training in interviewing and

+ Since the time of data collection in 2018-19, fuelled by the COVID pandemic, HAMSMaRT has undergone significant expansion and formalization of its programming. It continues to operate from its founding ethic of providing the care that people need where they need it. For more on HAMSMaRT's current programming, interdisciplinary model and organizational principles, please see hamsmart.ca.

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qualitative methods has been grounded in sensitive topics. Since the time of the study, she has taken on a larger leadership role in HAMSMaRT. The second author was a research associate with over 15 years of research experience and seven years of research experience in primary care. Two medical students were also involved in the project. Their role was to assist with data collection. They were not involved in analysis or report write-up. The first author was responsible for consistency between interviewers in terms of following the interview guide.

**Interview guide**

The interview questions and probes centred on the concept of quality of care, that is, what qualities of HAMSMaRT were characteristic of good health care. To contextualize HAMSMaRT within the broader (and mainstream) healthcare system, we also included questions about the quality of care in the mainstream healthcare system. To understand ways to improve HAMSMaRT, we included questions to explore any negative experiences and probed for ways to improve the service. The third author and a medical resident developed the interview guide. No substantial changes were made after the first interview, or at other times during data collection. See the Supplementary file for the interview guide.

**Procedure**

Upon university research ethics board approval (Hamilton-integrated Research Ethics Board Project #4500), participants were recruited. The third author recruited potential participants by inviting them (face-to-face). Participants were clearly informed that deciding not to participate in the study would not impact their care from HAMSMaRT. Interviews were conducted mostly by the first author in person, one-on-one, in the setting of the participant's choice including in hospital, in the participant's home or shelter or a coffee shop. The interviews were audio recorded. Data collection was stopped when it was deemed by this first author that the richness of the information was sufficient to answer the research question[12]. Participants were compensated for their time with a $50 gift card upon completion of the interview.

**Data analysis**

Audio recordings were intelligently and professionally transcribed. Pseudonyms were given to each participant and transcripts were de-identified. A reflexive thematic data analysis was employed.[13,14] We followed the six steps of thematic analysis. Specifically, we read and re-read the transcripts as well as re-listened to the audio-recordings to familiarize ourselves with the data. The first author generated initial codes through inductive coding grounded in the data. She then grouped codes together to make initial themes. The first and second authors reviewed potential themes by checking them against the data. We did this for each candidate theme and also across themes so as to review the potential viability of the entire story in the data. In team meetings we also defined and named themes. This phase involved staying true to the data while engaging with concepts from practice and research in this population. It was during this discussion that one allusive theme (*it's so simple*) crystallized. Finally, we produced a report that included a final thematic map. The thematic map was refined throughout the process. For example, team discussion took place to reflect on if, and how, the themes related to one another within the data. We reflected with our diverse experiences and historical knowledge developed working with people deprived of housing. This discussion led to *how* the final thematic looks and therefore represents the data and overall story. Data collection and analysis was concurrent.

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The analysis was grounded in a pragmatic framework[15] thus, rigour is driven by the research question. Since we wanted to explore participants' experiences with HAMSMaRT within the context of their experiences with the mainstream healthcare system, we used an interpretive approach to analysis. Authenticity, credibility, and trustworthiness of the data were upheld to foster quality of our approach.[16, 17] We display direct quotations from participants in the results (authenticity). Participants who were served directly by HAMSMaRT comprised the sample so as to gather information about experiences of this model of care. Also, participants had experiences with the mainstream healthcare system (e.g., emergency departments, hospitals, primary and specialist care) which meant they were able to articulate perceived differences and similarities between both models of care. Being able to speak about both models of care was important to the research question (credibility). We also use thick descriptions to contextualize our sample and local setting (credibility). Finally, the initial theme development was discussed and challenged (trustworthiness) among the authors whereby the team's different clinical, community and research perspectives strengthened analysis[18] and led to the final thematic map.

## RESULTS

A total of 14 people participated. There were no dropouts or refusals to participate. Interviews lasted between 45 and 90 minutes. Sixty-four percent of participants were female, and the average age was 48 years at time of interview (range 25-69). Primary medical diagnoses included HIV, Hepatitis C, chronic obstructive pulmonary disease, congestive heart failure, diabetes, opioid use disorder and alcohol use disorder. Sixty-four percent reported active substance use. Most of these conditions were complicated and compounded by the patients' living conditions, broadly speaking, either of being housebound (35%) or unhoused/precariously housed (65%).

Participants drew on their experiences with HAMSMaRT and a broad range of experiences within the mainstream healthcare system. It was through a juxtaposition of HAMSMaRT experiences to experiences with the mainstream healthcare system that a total of five themes were developed. These themes included: *people deserve care*, *from the margins to the centre*, *improved and different access to the system*, *it works!* and *it's so simple*.

### Thematic map overview

As shown in Figure 1, the first two themes, *People deserve care* and *from the margins to the centre* are tethered to one another. The third theme (*improved and different access to the system*) can only be realized when the theme *people deserve care* and *from the margins to the centre* are enacted. These three themes *people deserve care, from the margins to the centre*, and *improved and different access to the system* describe how HAMSMaRT was associated with higher patient satisfaction, engagement and ultimately better outcomes (*it works!*). The fifth theme is represented by the thematic map frame, containing the ethic (people deserve care, from the margins to the centre) the mechanism, (improved and different access to the system) and the improved outcomes (it works!) described by participants. The final thematic map was also hand-drawn to symbolize the fifth theme, *it's so simple*.

### People deserve care

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This theme represents the basic notion that patients of the healthcare system are human and deserving of dignity and respect by virtue of that fact alone. The theme *people deserve care* signals a recognition on the part of its patients of this founding ethic of HAMSMaRT.

*People deserve care* came to life in contradistinction to participant's experiences of the mainstream healthcare system that left them feeling they "did this to themselves" and thus did not deserve help and that care providers had more important people to serve. These interactions were lathered with judgment, blame, and insensitivity. One participant:

> The things that [the healthcare provider] had said to me, he said that I had done this to myself because of the choices that I've made [crying] in my life, that I was a horrible person, and then [my partner] just told him that he could basically go to hell, and she took me out and we left [crying] (Gail)

Participants repeatedly, reliably, and in great detail described dehumanizing and harmful exchanges that deterred them from seeking healthcare. Because of their treatment at the hands of the healthcare system, patients we interviewed both recognized and struggled to remember that they were 'more than a junkie' and not 'a child' or 'a number':

> Because it does make me feel worthless to have to go somewhere where I know I'm not going to be welcome for one, treated properly for another, and even care if I live or die sometimes I feel. You know? Sometimes I feel that there are some people in healthcare that think a dead junkie is a better junkie. You know? I really feel that there are people that feel that way. And that's sad. We are all human beings and we all have value. (Gabriel)

Another participant talked about prioritization by social status in mainstream healthcare provision, insinuating that some people are more important than others:

> But I find in the general healthcare system, they classify people. First off, and they really classify you if you have more than one or two strikes that are different, i.e. if you are on ODSP [Ontario Disability Support Program], addicted to opiates, a bit of an alcoholic, things like that, they are saying oh well, [...]let's get to the important people first and then we will get to him. (Demarcus)

Conversely, interactions between HAMSMaRT and participants were characterized by feelings of being treated as a human being with (equal) value. They described being engaged with respect, dignity, honesty, and genuine care. One participant described their experience with HAMSMaRT:

> There's not another doctor that I've ever met that will go to the lengths that HAMSMaRT does to try to save the people at the bottom of the rungs in society. And there are some people in the bottom of the rungs that have real value, that have real things to offer society. And that's what most people don't realize. We're not all pieces of crap. We're not all looking to hurt people and take from society. We ended up there through one situation or another, you know? We all have our own stories to tell about how we ended up there. But I have met so many addicts in my experience that have bigger hearts than

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> anybody I've ever met. And have more to offer society than a lot of people. If only someone showed them that they had value. If only someone cared for them, because they're dying out there. People who, if they really felt that somebody cared, that somebody was there for them, you know, it would make such a difference. And I think that's where HAMSMaRT comes in. (Gabriel)

Patients repeatedly described that working with providers who saw them as deserving affirmed or unearthed a belief in themselves that provided them with the will to keep going and to try to heal:

> I finally started advocating for myself. I was tired. I lost everything. And then I didn't see anybody offer me a way out. So I just thought more of the status quo. And so when you have people, like those doctors, [the HAMSMaRT doctor], I came out of the hospital the last time feeling like I have a plan with hope again. (Greta)

This humanizing approach to care, explicitly driven by the ethic that *people deserve care* was described as a way in which the patient was taken from the margins to the centre of their own care.

**From the margins to the centre**

This theme represents the participants' transformative experience of moving from the mainstream system's heretofore unrealized tenet of patient-centred care into a concrete practice of being the focus of their own care. This theme represents qualities of patient-centred and patient-focused care that are baked into HAMSMaRT and tethered to the previous theme (*people deserve care*).

While patient-centred care was recognized by participants as a rhetorical hallmark of the Ontario and Canadian mainstream healthcare systems writ large, it rarely characterized their experiences when accessing care. Over and over, participants described a throughline of their experiences as being judged, ignored, disregarded, discounted, excluded and silenced, in both hospital- and office-based care settings. Rowan summarized their experience:

> They just think that you can't do things. But the thing is that I can do a lot. I can't do everything. But I was in control of my own life and then other people were treating me like a child. And that's the way I felt at the doctors. I was being treated like a child. (Rowan)

Participants, often quite generously, attributed this decentering and patronizing behaviour on the part of providers to several organizational issues in the healthcare system, including heavy patient loads and provider fatigue. They primarily experienced it however, as a powerplay that elevated the physician at their own expense. Greta said:

> And I lost all trust in doctors. I lost all hope that I had. Not because they couldn't be good doctors, but it's…I'm the hero in this story too. You know what I mean? But they played God. (Greta)

Participants repeatedly asserted that healthcare providers didn't have a monopoly on health knowledge:

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> Just because we don't have a medical license, doesn't mean we don't know what's going on with our own bodies. We're the first person who knows what's going on with us. (Freya)

Centering the patient meant dissolving the well ingrained provider-patient (knowledge) hierarchy; recognizing and acting on the intelligence and experiential expertise that the patient brought to the table when making decisions about care. When this expertise is listened to, appreciated and worked with, shared decision making is realized. True to power-sharing is the notion that the provider and patient were equal in the relationship:

> [The HAMSMaRT doctor] doesn't act like he's saving me, and that's a huge difference, because I get to be a person and I get to be an expert on my own care. And so we can work together. And to me that is what I lost with everybody else. (Greta)

This kind of power sharing depends on provider affirmation of patient autonomy. Genuine respect for patient autonomy was experienced by patients as being listened to and believed. Believing and centering patients as experts in their own health experiences led to a bi-directional cycle of truth and trust previously unenjoyed. This power sharing enhanced the provider's ability to help and the patient's ability to heal. Greta continued:

> If I didn't have this…because as I said, I had lost all hope, all belief. I thought there wasn't any hope. So when I finally had people working for me, then it felt like…somebody is working with me and I will work with them. Yeah! We have hope now that I can get out of this mess. And I can have a future. (Greta)

These mutually reinforcing orientations to patient care of deserving and centering allowed for new and different access to care systems to which patients were at best, reticent about and at worst, deliberately avoiding.

**Improved and different access to the system**

This theme describes the well-known ways in which mobile, flexible, on call, health services are necessary to increase access to care. Importantly, however, the theme also elucidates how the HAMSMaRT model provides *improved and different* access to the wider healthcare system.

For all of the participants, logistical barriers to accessing care in the mainstream system were a major roadblock to improving their health. Patients described inaccessible offices, inflexible hours, difficulties navigating the system and complex and competing priorities in a provider-centred system that refused to recognize or address all of the barriers it erected:

> And I tried explaining it to them over the phone. I said 'I can't get out. I'm housebound.' 'Oh well, you have to come down and get these.' And I said, 'you want me to come all the way down just to pick up papers? It's not to see a doctor?' And she said 'yeah.' (Rowan)

Unsurprisingly, participants were extremely appreciative of HAMSMaRT's outreach model, which included ready access to physician support by phone, home/out of office visits and



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flexible scheduling. These "above and beyond" measures were viewed as a tangible enactment of the two previous themes:

> It helps because like I already said, it makes you feel important. It makes you feel special for one. So right away, you feel part of and willing to go and do whatever is required to go that extra mile to help these people, because they are coming all the way to my house. I'll certainly do what I can to help. If they're going to help me like this, then I'll help them help me. (Charlie)

Improved and different access, sometimes translated into less unnecessary use of health systems. Patients described the ways in which access to HAMSMaRT services meant they could stay out of the resource intensive emergency room, where previously (though they didn't want to) they had no choice but to go for care:

> It's incredible to have a doctor care for you and you can just text him and he's like OK, he calls the pharmacy. Or OK, I've got this going for you. Like [what happens when you start to develop an infection] Friday at 5 o'clock? Like go to the ER. And then you go through the whole process all over again. But if you have a doctor on hand like [the HAMSMaRT doctor], there's so many times when I've just called him and he's like, OK, I'm putting in something, a [prescription] or something like that. He's saved me so many times from having to go to the ER. (Nola)

Just as patients were moved by HAMSMaRT providers' decisions not to leverage their power against them, they were compelled by the way HAMSMaRT providers wielded their power *for* them; and sometimes miffed that it worked! In several instances, participants described scenarios that took the HAMSMaRT doctor's power as physician to communicate the patient's expertise, which led to care access:

> And all I called was [the HAMSMaRT doctor] and he called the [emergency room] doctor and boom I was in. It was…in a way it was frustrating, but in a way I was so relieved, you know? It was like a double-edged sword. It was like you fucking bastards. Pardon my language. But really that's what I thought. You bastards. Like this is my third visit in a week and all it took was one call from [the HAMSMaRT doctor]. OK, this patient has this, this, this, which I told them I had, which I told them I thought I had. And he repeated every single thing I said, probably to the tee and they listened to him and not to me. You know what I mean? That's not fair, you know? And I even said to him, what did you say to them? And he said, 'pretty much what you said.' He's like, 'yeah I know, it's OK. One problem at a time Freya', that's what he said, 'one problem at a time.' (Freya)

Importantly, this improved and different access also meant that patients who had previously struggled to stay in the hospital (for the maltreatment they had become so accustomed to) now could. This participant shared how their involvement with HAMSMaRT changed their access to the mainstream healthcare system:

> In hospitals, I've always been treated differently than other patients because I have an addiction. And I don't think it's fair that I should be left to suffer in pain. I have pain

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> issues and significant pain issues that are well documented and all verified through imaging and things like that. And since I've been dealing with HAMSMaRT [...], when I'm in the hospital, I feel like I'm treated differently now, right? Because [the HAMSMaRT doctor] always has some involvement in my care [...]. So when it comes to my pain issues and things like that, they try their best to deal with it. And I've never felt like any healthcare institution has ever tried their best on my behalf. And I feel that now. And I truly believe it's because of the involvement of HAMSMaRT. (Gabriel)

Finally, some participants described a renewed trust in possibilities of healthcare, stemming from the advocacy efforts of HAMSMaRT:

> Well working with [the HAMSMaRT doctor] made me come to terms of learning to trust doctors more than what I did, because I never really had any doctors that I wanted to see. If I was sick I dealt with it. And then something like this happens. So for that year that I had the infection, it was like I'm going to conquer this, I'm going to kill it. No two ways about it. Nobody is taking my leg or whatever. And then it so happens that the inevitable happens. Maybe I should listen to doctors a lot more. For me that's my learning experience. Now I kind of have to trust doctors and nurses more. If they say well maybe you should do this, then that's what I'm going to do. (Marlow)

These tangible and behind the scenes strategies alike were described by participants as helping them access care, leading to improvement in health, i.e. it worked!

**It works!**

For many people accessing a publicly funded healthcare system, the answer to the question of "how do you know you got good care?" takes for granted that, to the extent possible, the healthcare improved the person's health. Participant responses to this question were simple, humble and profound. Their responses spoke to how, when the three themes are brought to life, the model of care (i.e., HAMSMaRT) works. Startlingly, participants described having health improvements as the way they knew they were getting good care:

> Just seeing results, seeing the results of me getting better is proof in itself that I know that what they are doing is working. (Isla)

Freya also felt "better" since being involved with HAMSMaRT. Demarcus told us:

> There is no doubt. 100%. Because it was constant care. Difference in between waiting until I got sick and then going, then acting or reacting to that. As opposed to acting and the outcome being instead gratifying. Yeah. I felt much more at ease knowing that I could talk to him and be pointed in the right direction. (Demarcus)

Again, participants drew conclusions about their success with HAMSMaRT by drawing on, and comparing to, their experiences with the provider-centred health care system:

> And you know, I had lost 100lbs since [major life event]. Since I've actually been getting what I think is quality healthcare, I've gained 45 of that back. Even though I was still using, I've had people say wow you look better than you've looked since [that major life

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> event]. And I even feel it. I feel better. I look better. I'm more engaged in life. I care more about my life now. So those are the things that I think prove to me that my healthcare is better now than it was before. (Gabriel)

Participants spoke about hope and engagement in life as outcomes of their involvement with HAMSMaRT. Rowan described the profound impact of the simplicity of the HAMSMaRT approach:

> And [the HAMSMaRT doctor] came down and talked to me about stuff, and I [...] actually had given up on living. And he sat and talked to me, and said don't give up. Let's try this, we'll do this, we'll work on this. And he was giving me all these other ideas where when my family doctor dropped me and my liver doctor wasn't doing her job properly, I had just given up. I just wanted to curl up and die. And he got me back into wanting to fight to live. So that's why I'm still here. (Rowan)

Some participants expressed optimism that HAMSMaRT could lead to change in the system through replication and scaling up:

> It's amazing. You guys are doing something…I don't know what the word is for it. Like um…ground changing, or groundbreaking. Really. If more people can have this, it's going to change the way they feel about doctors and medicine. You guys really helped me. (Freya)

There was even a glimpse of restored faith in the possibility of healthcare that heals - "I actually believe now in care [...] and I just love not being sick anymore." (Isla)

In an increasingly technocratic, regimented and strained healthcare system it's impossible to miss the simplicity of what patients have here described as setting their experiences apart from those of the larger healthcare system.

**It's so simple**

There was a tone to the interviews that speaks to the simplicity of what participants viewed as requisite to a healing process. One keen and insightful participant summed it up very succinctly:

> It really is [that simple] and I don't see why it seems so hard sometimes in the hospitals. Just treat a person as a person. That's the biggest thing that could be adopted from HAMSMaRT to the healthcare system overall. (Gabriel)

Isla brought this theme of simplicity into stark reveal describing her perception of a shift in her care since working with HAMSMaRT. She said that it was the likelihood that she wouldn't be treated "like shit" that enabled her to seek the care she needed. It doesn't get much simpler than that.

For our team, many of the strategies participants described are things we already know improve access and quality of care. One participant with extensive experience as an inpatient described a small interaction that stood out from all her time spent in hospital:

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> I moved to the B wing after the E wing, and the nurse came in and I expected something. So I was like, oh, did you need me to sign something or did you need something? She goes, no I'm just coming to say hi and tell you that I'm your nurse and my name is so-and-so. And she left. And I was like holy crap. That was like…that made me feel so good and it was 2 seconds…I think that's what makes it so frustrating, is that there is not much to it. (Nola)

Here a two second interaction made the difference. Simple.

**DISCUSSION**

Our study explored the experiences of people involved in HAMSMaRT in the context of their access to and quality of care within the overall healthcare system. Our findings provide evidence that HAMSMaRT brings to life the principles that people deserve care and should be at the centre of it, leading to improved and different access to the system. When these three things are enacted, the model of care (HAMSMaRT) works. The profundity and simplicity of what patients described as quality care as realized through HAMSMaRT, and how elusive it was in the mainstream healthcare system, should give us all pause as health providers.

Our findings corroborate those of Wen and colleagues'[19] exploration of the dehumanization of people experiencing homeless by the healthcare system. They frame patient experiences as welcoming versus unwelcoming, noting that the latter's stigmatizing ethic, like in our findings of patient experiences in the mainstream health system, leads to system aversion. Our findings also parallel those of Bouchelle et al.'s[20] exploration of the experiences of medically vulnerable people accessing a mobile health van in Boston. Bouchelle et al. found that in addition to accessible communication styles, a diverse and knowledgeable workforce, and conveniently located services, a culture of respect and dignity aboard the outreach clinic was central in facilitating access to service.

Our findings also contribute to the growing evidence that mobile health clinics are effective in improving health outcomes of equity deserving people.[6,8,9] They further contribute to the small body of qualitative evidence for the effectiveness of mobile health clinics that serve people who are deprived of housing.[3] While recent qualitative work[1,19,20] explored why people use a mobile health clinic (accessing basic necessities, convenience, friendly atmosphere), our findings probe *what* it is about the model that works. Our findings describe the nuances of quality care and help to elucidate the *what* and the *how* behind the quantitative evidence of the effectiveness of mobile health clinics. In essence, our findings flesh out and affirm Wen et al.'s[19] suggestion that "the provision of effective care may be tied to the ability to create a welcoming environment."

Research about care of equity deserving populations primarily directs its gaze at either the patients of, or providers to, the population in question. The sizable body of work around patient barriers to and experiences of health care is congruent with our findings that stigma and discrimination are major deterrents to care and barriers to improved health outcomes.[21-23] There is a smaller body of work on the experiences of providers caring for equity deserving populations which enumerates the difficulties of providing welcoming, high-quality care within the confines of the provider-centred health system; these difficulties include providing humanized service in a

stigmatizing health care milieu.[24-27] There are some efforts described in the literature to develop methods for combating the deterring stigmatizing nature of health systems[28-30]; however, there is little work done to excavate what undergirds such stigmatizing care delivery. Our findings and the existing literature demonstrate that there is a disjoint between the widely adopted rhetoric of patient-centred care and the actual practice by a critical mass of providers. Exploring this, perhaps through the perceptions and experiences of providers in the mainstream healthcare system, is an area of study rife with transformational potential.

A few caveats should be acknowledged. Our findings come from a group of participants who were involved with one type of mobile health clinic. Although the goal of qualitative research is not to generalize, we provide enough rich description to contextualize both the sample and HAMSMaRT for transferability of our findings to similar contexts. There may be contextual factors like population-level characteristics (e.g., racial or ethnic background, language) or system-wide policies or funding structures that make transferability difficult. Additionally, the constitution and size of our sample precluded us taking intersectional approach to understanding the layered stigma (and multi-stigma), discrimination and racism meted out by the health system. Also missing is the healthcare provider perspective; why might this model work for patients from the viewpoint of the provider?

We share these findings, lauding the HAMSMaRT model, with humility and in deference to the brilliance of the patients with whom we work. While we hope that the insights shared by participants will be taken up by others striving to provide better care, we also commit to implementing these findings in our own growing and changing organization. Since the time of data collection in 2018 we continue to bridge the gap between the community and hospital care. We have secured semi-stable funding, expanded and consolidated our services through a formal partnership with a user-led harm reduction group in the city, established a multi-site safer supply program for people using opioids, incorporated psychiatry and primary care into our clinical model and expanded our organizational team. We strive to extrapolate the lessons learned from these descriptions of the one-on-one patient interactions to our own HAMSMaRT "health system"; we take our lead as a healthcare organization from our patients and the community to which we all belong. All of our work begins from the principle that people deserve care that centres them, which allows us to provide improved and different access to healthcare - it works and it is that simple.

## CONTRIBUTORSHIP STATEMENT

LN and TO were responsible for research idea conception, methodology planning and participant recruitment. LN was responsible data collection oversight and coding. LN and LL were responsible for data analysis. LN, LL and TO all contributed to data interpretation and were engaged in the reflexive practice in data analysis. LN, LL and TO contributed to report writing and knowledge translation activities.

## ACKNOWLEDGEMENTS

The authors wish to thank and acknowledge, first and foremost the HAMSMaRT patients and participants who have shared their lives and experiences with us as providers and researchers. We hope that this paper does your ideas and insights justice. We would also like to thank Dr. Sheiry Dhillon for her input into the early phases of the overall project to develop an evaluation

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tool for mobile outreach clinics. Thank you to Jane Tooley and Jesse Bauman for conducting some of the interviews in this project. Thank you also to Dr. Nicole Buchanan for her contributions to the background research for the project.

**COMPETEING INTERESTS**

We have no competing interests or conflicts of interests to declare.

**FUNDING STATEMENT**

This work was not funded.

**DATA SHARING STATEMENT**

Deidentified data will be shared upon responsible request by contacting the corresponding author.

**ETHICS APPROVAL**

Ethics approval for this project was received through the Hamilton-integrated Research Ethics Board (Project #4500).

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## REFERENCES

1 Whelan C, Chambers C, Chan M, Thomas S, Ramos G, Hwang SW. Why do homeless people use a mobile health unit in a country with universal health care?. *J Prim Care Community Health* 2010;1(2):78-82. https://doi.org/10.1177/2150131910372233

2 Giesbrecht M, Stajduhar KI, Mollison A, Pauly B, Reimer-Kirkham S, McNeil R, Wallace B, Dosani N, Rose C. Hospitals, clinics, and palliative care units: Place-based experiences of formal healthcare settings by people experiencing structural vulnerability at the end-of-life. *Health Place* 2018;53:43-51. https://doi.org/10.1016/j.healthplace.2018.06.005

3 Harris M. Normalised pain and severe health care delay among people who inject drugs in London: Adapting cultural safety principles to promote care. *Soc Sci Med* 2020;260:113183. https://doi.org/10.1016/j.socscimed.2020.113183

4 McNeil R, Small W, Wood E, Kerr T. Hospitals as a 'risk environment': an ethno-epidemiological study of voluntary and involuntary discharge from hospital against medical advice among people who inject drugs. *Soc Sci Med* 2014;105:59-66. https://doi.org/10.1016/j.socscimed.2014.01.010

5 Shortt SE, Hwang S, Stuart H, Bedore M, Zurba N, Darling M. Delivering primary care to homeless persons: a policy analysis approach to evaluating the options. *Healthc Policy* 2008;4(1):108.

6 Yu SW, Hill C, Ricks ML, Bennet J, Oriol NE. The scope and impact of mobile health clinics in the United States: a literature review. *Int J for Equity Health* 2017;16(1):1-12. https://doi.org/10.1186/s12939-017-0671-2

7 Oriol NE, Cote PJ, Vavasis AP, Bennet J, DeLorenzo D, Blanc P, Kohane I. Calculating the return on investment of mobile healthcare. *BMC Med* 2009;7(1):1-6.

8 Egwu, E. Mobile health clinic as a medium for reducing health disparities in underserved populations. Dissertation Georgia State University 2019. https://scholarworks.gsu.edu/nursing_dnpprojects/15

9 Jimenez A. The use of mobile healthcare clinics to expand access to underserved populations: a rapid review. Undergraduate honors thesis Central Washington University 2019 https://digitalcommons.cwu.edu/undergrad_hontheses/14

10 Liamputtong, P. Qualitative Research Methods, 4th Ed. Melbourne: Oxford University Press 2013.

11 Patton MQ. Qualitative Research and Evaluation Methods, 3rd Ed. Thousand Oaks, CA: Sage 2002.

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12 Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qual Res Sport Exer Health* 2019; 13:1-16.

13 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psych* 2006;*3:* 77-101. https://doi.org/10.1191/1478088706qp063oa

14 Braun, V, Clarke, V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exer Health* 2019;*11*(4): 589-597.

15 Morgan DL. Pragmatism as a paradigm for social research. *Qual Inq* 2014;20:1045-1053. https://doi.org/10.1177/1077800413513733

16 Lincoln YS, Guba EG. But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New Dir Eval* 1989; 30:73-84.

17 Tracy SJ. Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. *Qual Inq* 2010;16(10): 837-851. https://doi.org/10.1177/1077800410383121

18 Patton MQ. Enhancing the quality and credibility of qualitative analysis. *Health Serv Res* 1999;34:1189-1208.

19 Wen CK, Hudak, PL, Hwang SW. Homeless people's perceptions of welcomeness and unwelcomeness in healthcare encounters. *J Gen Intern Med* 2007;22:1011-1017.

20 Bouchelle Z, Rawlins Y, Hill C, Bennet J, Perez LX, Oriol N. Preventative health, diversity, and inclusion: a qualitative study of client experience aboard a mobile health clinic in Boston, Massachusetts. *Int J Equity Health* 2007;16:191. https://doi.org/10.1186/s12939-017-0688-6

21 Kalich A, Heinemann L, Ghahari SA. Scoping review of immigrant experience of health care access barriers in Canada. *J Immigr Minor Health* 2016;18:697-709. https://doi.org/10.1007/s10903-015-0237-6

22 Ramsay N, Hossain R, Moore M, Milo M, Brown A. Health care while homeless: barriers, facilitators, and the lived experiences of homeless individuals accessing health care in a Canadian regional municipality. *Qual Health Res* 2019;29(13):1839-1849. https://doi.org/10.1177/1049732319829434

23 Monchalin, R, Smylie J, Nowgesic E. "I Guess I Shouldn't Come Back Here":racism and discrimination as a barrier to accessing health and social services for urban Métis women in Toronto, Canada. *J Racial Ethn Health Disparities* 2019;7(2)251-261. https://doi.org/10.1007/s40615-019-00653-1

24 McKeary M, Newbold, B. Barriers to care: the challenges for Canadian refugees and their health care providers. *J Refug Stud* 2010;23(4):523-545. https://doi.org/10.1093/jrs/feq038

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25 Loignon C, Hudon C, Goulet É, Boyer S, De Laat M, Fournier N, Grabovschi C, Bush P. Perceived barriers to healthcare for persons living in poverty in Quebec, Canada: the EQUIhealThY project. *Int J Equity Health* 2015;14(1):1-11. https://doi.org/10.1186/s12939-015-0135-5

26 Campbell DJ, O'Neill BG, Gibson K, Thurston WE. Primary healthcare needs and barriers to care among Calgary's homeless populations. *BMC Fam Pract* 2015;16:1-10. https://doi.org/10.1186/s12875-015-0361-3

27 Darling EK, MacDonald T, Nussey L, Murray-Davis B, Vanstone M. Making midwifery services accessible to people of low SES: a qualitative descriptive study of the barriers faced by midwives in Ontario. *Can J Midwif Res Pr* 2020;19(2):1-13.

28 Stuart H, Chen SP, Christie R, Dobson K, Kirsh B, Knaak S, Koller M, Krupa T, Lauria-Horner B, Luong D, Modgill G. Opening minds in Canada: targeting change. *Can J Psychiatry* 2014;59(suppl):13-18. https://doi.org/10.1177/070674371405901S05

29 Stuart H. Managing the stigma of opioid use. *Healthcare Management Forum* 2019;32(2):78-83. https://doi.org/10.1177/0840470418798658

30 Ungar T, Knaak S, Szeto AC. Theoretical and practical considerations for combating mental illness stigma in health care. *Community Ment Health J* 2016;52(3):262-71. https://doi.org/10.1007/s10597-015-9910-4

**FIGURE LEGEND**
Thematic map

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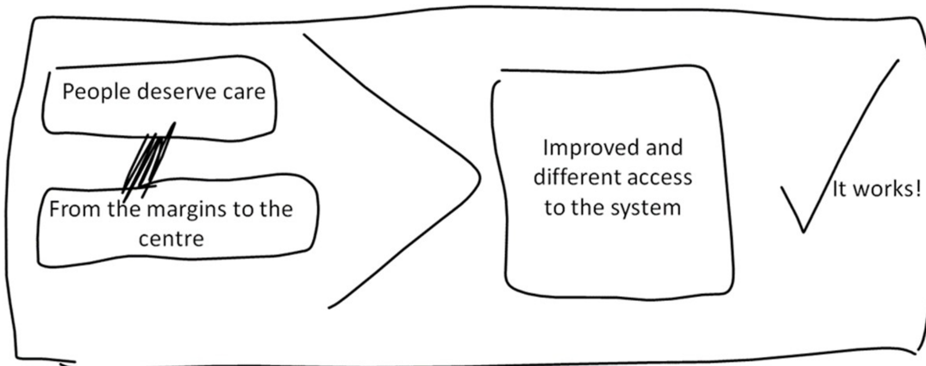


*Note.* It's so simple

Thematic map

338x190mm (96 x 96 DPI)

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**Supplementary File. Interview guide**

1. How would you describe your experiences with HAMSMaRT so far?
    a. How did you first encounter the program?
    b. How do you think HAMSMaRT's services could be improved?
        i. Was there a specific time when HAMSMaRT didn't meet your needs?
    c. What is it about HAMSMaRT that you feel would be good to apply in other similar programs?
2. Can you tell me about any experiences when you felt like you got good quality care?
    a. What changes would you like to see in the healthcare system to better serve your needs?
    b. How do you know when you've received good quality care? Some people say it's a feeling they get or it's their physical health that's improved – what is it for you?
3. Based on your experiences, what was a time when you received poor quality health care?
    a. How do you know when you've received poor quality care? Is it a feeling, a change in your physical health, or something else?
    b. Have there been times when you weren't treated well? If so, what happened that made you feel that way?
    c. Have you ever experienced stigma while getting care? If so, how did it affect the care you received?
    d. Why do you think you received poor care?
4. What barriers have you experienced in accessing health care?
    a. What was the effect of those barriers on your ability to get care?
    b. How could your access to health care have been improved?
5. In general, what qualities do you hope for in a doctor?
    a. How do you like to make decisions with your doctor?
    b. What are the most important things to you to have a good relationship with your doctor?
    c. What kind of relationship do you like to have with your doctor?
    d. What training do you think docs/HC providers are missing to provide better care?

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**Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist**

| No. Item | Guide questions/description | Reported on Page # |
|---|---|---|
| **Domain 1: Research team and reflexivity** | | |
| *Personal Characteristics* | | |
| 1. Inter viewer/facilitator | Which author/s conducted the interview or focus group? | 5 |
| 2. Credentials | What were the researcher's credentials? E.g. PhD, MD | 4-5 |
| 3. Occupation | What was their occupation at the time of the study? | 4-5 |
| 4. Gender | Was the researcher male or female? | 4-5 |
| 5. Experience and training | What experience or training did the researcher have? | 4-5 |
| *Relationship with participants* | | |
| 6. Relationship established | Was a relationship established prior to study commencement? | 5-6 |
| 7. Participant knowledge of the interviewer | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research | 6 |
| 8. Interviewer characteristics | What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | 4-5 |
| **Domain 2: study design** | | |
| *Theoretical framework* | | |
| 9. Methodological orientation and Theory | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | 6 |
| *Participant selection* | | |
| 10. Sampling | How were participants selected? e.g. purposive, convenience, consecutive, snowball | 5 |
| 11. Method of approach | How were participants approached? e.g. face-to-face, telephone, mail, email | 5 |
| 12. Sample size | How many participants were in the study? | 6 |
| 13. Non-participation | How many people refused to participate or dropped out? Reasons? | 6 |
| *Setting* | | |
| 14. Setting of data collection | Where was the data collected? e.g. home, clinic, workplace | 5-6 |
| 15. Presence of non-participants | Was anyone else present besides the participants and researchers? | 5 |

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|---|---|---|
| 16. Description of sample | What are the important characteristics of the sample? e.g. demographic data, date | 6 |
| *Data collection* | | |
| 17. Interview guide | Were questions, prompts, guides provided by the authors? Was it pilot tested? | Supplemental file |
| 18. Repeat interviews | Were repeat interviews carried out? If yes, how many? | No, no follow-up was deemed necessary |
| 19. Audio/visual recording | Did the research use audio or visual recording to collect the data? | 5 |
| 20. Field notes | Were field notes made during and/or after the interview or focus group? | No, we did not use this strategy to foster rigor, but used others |
| 21. Duration | What was the duration of the inter views or focus group? | 6 |
| 22. Data saturation | Was data saturation discussed? | 5 |
| 23. Transcripts returned | Were transcripts returned to participants for comment and/or correction? | No, we did not use this strategy to foster rigor, but used others. |
| **Domain 3: analysis and findings** | | |
| *Data analysis* | | |
| 24. Number of data coders | How many data coders coded the data? | 5-6 |
| 25. Description of the coding tree | Did authors provide a description of the coding tree? | 6 |
| 26. Derivation of themes | Were themes identified in advance or derived from the data? | 5 |
| 27. Software | What software, if applicable, was used to manage the data? | Not applicable |
| 28. Participant checking | Did participants provide feedback on the findings? | No, we did not use this strategy to foster rigor, but used others. |
| *Reporting* | | |
| 29. Quotations presented | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number | 6-13 |
| 30. Data and findings consistent | Was there consistency between the data presented and the findings? | 6-13 |
| 31. Clarity of major themes | Were major themes clearly presented in the findings? | 6-13 |
| 32. Clarity of minor themes | Is there a description of diverse cases or discussion of minor themes? | Not applicable; did not emerge in our analysis |

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# “It’s so simple!” Lessons from the margins: A qualitative study of patient experiences of a mobile health clinic in Hamilton, Ontario, Canada



| Journal: | *BMJ Open* |
|---|---|
| Manuscript ID | bmjopen-2022-066674.R2 |
| Article Type: | Original research |
| Date Submitted by the Author: | 17-Feb-2023 |



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| <b>Primary Subject Heading</b>: | Patient-centred medicine |
|---|---|
| Secondary Subject Heading: | Qualitative research |
| Keywords: | Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, PRIMARY CARE, QUALITATIVE RESEARCH |


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# "It's so simple!" Lessons from the margins: A qualitative study of patient experiences of a mobile health clinic in Hamilton, Ontario, Canada

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**Keywords**: mobile health care clinics, qualitative research, under-served, homeless, people deprived of housing, patient-centred care

**Word Count**: 6100

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**Abstract**

**Objective**: Our study explored the experiences of clients of HAMSMaRT (Hamilton Social Medicine Response Team), a mobile health service, in the context of their experiences of the overall healthcare system. **Design**: We conducted a qualitative study with reflexive thematic analysis. **Setting**: HAMSMaRT is a mobile health service in Hamilton, Ontario Canada 'providing primary care, internal medicine and infectious diseases services. **Participants**: Eligible participants were clients of HAMSMaRT who could understand English to do the interview and at least 16 years of age. Fourteen clients of HAMSMaRT were interviewed. **Results**: Our findings represented five themes. When the themes of *people deserve care, from the margins to the centre*, and *improved and different access to the system* are enacted, the model of care works, represented by the theme *it works!*. The way in which participants compared their experiences of HAMSMaRT to the mainstream healthcare system insinuated how simple it is, represented by the theme *it's so simple*. **Conclusions**: Our findings offer guidance to the broader healthcare system for walking from the rhetoric to practice of person-centred care.

**Keywords**: mobile health care clinics, qualitative research, under-served, homeless, people deprived of housing, patient-centred care

**Strengths and limitation of this study**

- Adds to the small body of existing health service literature that represents and centres the client perspectives of a mobile health service
- Authenticity, credibility, and trustworthiness of the data were upheld to foster quality of our approach
- Group of participants who were involved with one type of mobile health clinic interviewed
- Constitution and size of sample preclude an intersectionality approach

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## INTRODICTION

Despite a model of *universal* health care in Canada, provider-centred health services create physical and logistic barriers to access.[1] It has also been well documented that barriers to health care for patients who are deprived of housing and/or who use drugs are exacerbated by stigma, structural violence, and a lack of cultural safety in the healthcare setting, leading to poor health outcomes including inadequate withdrawal management, inadequate treatment of pain, premature discharges, and avoidance of medical care altogether.[2-4]

Mobile health services offer a particularly crucial supplement to other sources of health care for patients who are deprived of housing and who are not well served by the status quo model of medical care delivery.[1,5] They have been shown to be effective in meeting the health needs of (health) equity-deserving populations by providing services directly in patients' own environment, decreasing geographic/logistic barriers to accessing mainstream health care services. Additionally, mobile services have been shown to foster trusting patient-provider relationships, and the ability to better address the social determinants of health through connecting patients to wider community resources.[6] Mobile health services have also been shown to decrease health care costs, by helping to avoid unnecessary emergency department visits and hospital admissions.[6,7]

A review of published literature on the scope and impact of mobile health clinics in the United States,[6] and grey literature,[8,9] demonstrates that mounting evidence of the effectiveness of mobile health clinics is largely quantitative. Some scholars[6] have called for future research to explore the strengths of mobile health clinics versus traditional care models from the client perspective. In addition, research of mobile health clinics is scarce for people who are deprived of housing. One qualitative study in Toronto showed that mobile health programs can provide convenient, non-judgmental care for homeless patients who are poorly served by the mainstream medical system.[1] Thus, the aim of this study is to explore client experiences of HAMSMaRT (Hamilton Social Medicine Response Team), a mobile, physician-led service, in the context of their access to and quality of care within the overall healthcare system. Our research question was, what is the patient experience of HAMSMaRT as part of their overall experience within the healthcare system?

## STUDY SETTING

The study reported here is part of a larger study which aimed to create an evaluation tool for mobile outreach clinics, via a clinician-centred Delphi consensus process and patient-generated quality of care indicators. Results of the larger study will be reported elsewhere.

### Broader local context

Our study took place in Hamilton Ontario, an urban setting with an overall population of 776,000 people. At the time of the data collection, a number of health care services in Hamilton (e.g., Shelter Health Network, Refuge Centre for Newcomer Health, North Hamilton and Urban Core Community Health Centres, etc.) were mandated to serve equity-deserving populations. These services, however, are almost exclusively provided in a fixed, office environment where patients must travel to the provider, at specified appointment or drop-in times, for necessary medical care, while some clinics are co-located with existing social services (e.g., shelters, drop-ins). There are a handful of clinical outreach services which provide nursing or midwifery care, but

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few offer primary/physician care. The landscape has shifted marginally since and during COVID, but by and large, primary care for our study population is provided in a clinic setting.

**Description of HAMSMaRT[+]**

The Hamilton Social Medicine Response Team was founded in 2016 by two internal medicine physicians as a simple, ethical, intervention to support their patients in accessing much needed, but often not received, health care. The HAMSMaRT model was born of genuine listening and responding to patient concerns and desires about, and for, their own health and healthcare. HAMSMaRT is a mobile, interdisciplinary service that strives to provide care to individuals who otherwise have difficulty accessing care in the mainstream system, at a location where they are most comfortable. Patients, broadly speaking, are deprived of housing and are either unhoused/precariously housed, or unable to leave their homes primarily due to mobility difficulties. HAMSMaRT aimed to provide care where patients were most comfortable receiving it, for example in their homes, shelter spaces, coffee shops and park benches. At the time of data collection, HAMSMaRT had a patient base of 200 individuals. HAMSMaRT works toward bridging the gap between the community and hospital services, establishing close relationships and formal partnerships with clinical programs and community organizations serving equity-deserving people in Hamilton.

## METHODS

We used a qualitative study design. We chose a qualitative study so that we could explore perspectives of the people who use HAMSMaRT and capture the nuances of the patient experience with HAMSMaRT. One-on-one semi-structured interviews were conducted. The interviews took place between April of 2018 to May of 2019.

**Patient and Public Involvement**

No patient or public involved in methodology development.

**Participants**

All participants were patients of HAMSMaRT, which meant they lived in Hamilton, Ontario and struggled to access care through conventional modes. Participants for this study also had to be at least 16 years of age and understand English enough to engage with the interviewer. Participants were purposefully sampled[10,11] by the third author from his patient roster.

**Research team**

The research team consisted of 3 people. The team was a mix of clinicians and researchers involved with HAMSMaRT and working within addiction medicine. All authors endorsed a harm reduction approach to addiction and clinical care more broadly. At the time of the study, the third author was an infectious disease specialist with expertise in addiction medicine and low-barrier care for people who use drugs. He was a co-founder of HAMSMaRT. The first author was a registered midwife completing her masters in Health Research Methods. People accessing HAMSMaRT can have a distrust with healthcare providers and the healthcare system;

[+] Since the time of data collection in 2018-19, fuelled by the COVID pandemic, HAMSMaRT has undergone significant expansion and formalization of its programming. It continues to operate from its founding ethic of providing the care that people need where they need it. For more on HAMSMaRT's current programming, interdisciplinary model and organizational principles, please see hamsmart.ca.

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however, she had experience working with people who used HAMSMaRT, thus had the knowledge and rapport to conduct the interviews. Also, her training in interviewing and qualitative methods has been grounded in sensitive topics. Since the time of the study, she has taken on a larger leadership role in HAMSMaRT. The second author was a research associate with over 15 years of research experience and seven years of research experience in primary care. Two medical students were also involved in the project. Their role was to assist with data collection. They were not involved in analysis or report write-up. The first author was responsible for consistency between interviewers in terms of following the interview guide.

**Interview guide**

The interview questions and probes centred on the concept of quality of care, that is, what qualities of HAMSMaRT were characteristic of good health care. To contextualize HAMSMaRT within the broader (and mainstream) healthcare system, we also included questions about the quality of care in the mainstream healthcare system. To understand ways to improve HAMSMaRT, we included questions to explore any negative experiences and probed for ways to improve the service. The third author and a medical resident developed the interview guide. No substantial changes were made after the first interview, or at other times during data collection. See the Supplementary file for the interview guide.

**Procedure**

Upon university research ethics board approval (Hamilton-integrated Research Ethics Board Project #4500), participants were recruited. The third author recruited potential participants by inviting them (face-to-face). Participants were clearly informed that deciding not to participate in the study would not impact their care from HAMSMaRT. Interviews were conducted mostly by the first author in person, one-on-one, in the setting of the participant's choice including in hospital, in the participant's home or shelter or a coffee shop. The interviews were audio recorded. Data collection was stopped when it was deemed by this first author that the richness of the information was sufficient to answer the research question[12]. Participants were compensated for their time with a $50 gift card upon completion of the interview.

**Data analysis**

Audio recordings were intelligently and professionally transcribed. Pseudonyms were given to each participant and transcripts were de-identified. A reflexive thematic data analysis was employed.[13,14] We followed the six steps of thematic analysis. Specifically, we read and re-read the transcripts as well as re-listened to the audio-recordings to familiarize ourselves with the data. The first author generated initial codes through inductive coding grounded in the data. She then grouped codes together to make initial themes. The first and second authors reviewed potential themes by checking them against the data. We did this for each candidate theme and also across themes so as to review the potential viability of the entire story in the data. In team meetings we also defined and named themes. This phase involved staying true to the data while engaging with concepts from practice and research in this population. It was during this discussion that one allusive theme (*it's so simple*) crystallized. Finally, we produced a report that included a final thematic map. The thematic map was refined throughout the process. For example, team discussion took place to reflect on if, and how, the themes related to one another within the data. We reflected with our diverse experiences and historical knowledge developed

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working with people deprived of housing. This discussion led to *how* the final thematic looks and therefore represents the data and overall story. Data collection and analysis was concurrent.

The analysis was grounded in a pragmatic framework[15] thus, rigour is driven by the research question. Since we wanted to explore participants' experiences with HAMSMaRT within the context of their experiences with the mainstream healthcare system, we used an interpretive approach to analysis. Authenticity, credibility, and trustworthiness of the data were upheld to foster quality of our approach.[16, 17] We display direct quotations from participants in the results (authenticity). Participants who were served directly by HAMSMaRT comprised the sample so as to gather information about experiences of this model of care. Also, participants had experiences with the mainstream healthcare system (e.g., emergency departments, hospitals, primary and specialist care) which meant they were able to articulate perceived differences and similarities between both models of care. Being able to speak about both models of care was important to the research question (credibility). We also use thick descriptions to contextualize our sample and local setting (credibility). Finally, the initial theme development was discussed and challenged (trustworthiness) among the authors whereby the team's different clinical, community and research perspectives strengthened analysis[18] and led to the final thematic map.

## RESULTS

A total of 14 people participated. There were no dropouts or refusals to participate. Interviews lasted between 45 and 90 minutes. Sixty-four percent of participants were female, and the average age was 48 years at time of interview (range 25-69). Primary medical diagnoses included HIV, Hepatitis C, chronic obstructive pulmonary disease, congestive heart failure, diabetes, opioid use disorder and alcohol use disorder. Sixty-four percent reported active substance use. Most of these conditions were complicated and compounded by the patients' living conditions, broadly speaking, either of being housebound (35%) or unhoused/precariously housed (65%).

Participants drew on their experiences with HAMSMaRT and a broad range of experiences within the mainstream healthcare system. It was through a juxtaposition of HAMSMaRT experiences to experiences with the mainstream healthcare system that a total of five themes were developed. These themes included: *people deserve care*, *from the margins to the centre*, *improved and different access to the system*, *it works!* and *it's so simple*.

### Thematic map overview

As shown in Figure 1, the first two themes, *People deserve care* and *from the margins to the centre* are tethered to one another. The third theme (*improved and different access to the system*) can only be realized when the theme *people deserve care* and *from the margins to the centre* are enacted. These three themes *people deserve care, from the margins to the centre*, and *improved and different access to the system* describe how HAMSMaRT was associated with higher patient satisfaction, engagement and ultimately better outcomes (*it works!*). The fifth theme is represented by the thematic map frame, containing the ethic (people deserve care, from the margins to the centre) the mechanism, (improved and different access to the system) and the improved outcomes (it works!) described by participants. The final thematic map was also hand-drawn to symbolize the fifth theme, *it's so simple*.



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**People deserve care**

This theme represents the basic notion that patients of the healthcare system are human and deserving of dignity and respect by virtue of that fact alone. The theme *people deserve care* signals a recognition on the part of its patients of this founding ethic of HAMSMaRT.

*People deserve care* came to life in contradistinction to participant's experiences of the mainstream healthcare system that left them feeling they "did this to themselves" and thus did not deserve help and that care providers had more important people to serve. These interactions were lathered with judgment, blame, and insensitivity. One participant:

> The things that [the healthcare provider] had said to me, he said that I had done this to myself because of the choices that I've made [crying] in my life, that I was a horrible person, and then [my partner] just told him that he could basically go to hell, and she took me out and we left [crying] (Gail)

Participants repeatedly, reliably, and in great detail described dehumanizing and harmful exchanges that deterred them from seeking healthcare. Because of their treatment at the hands of the healthcare system, patients we interviewed both recognized and struggled to remember that they were 'more than a junkie' and not 'a child' or 'a number':

> Because it does make me feel worthless to have to go somewhere where I know I'm not going to be welcome for one, treated properly for another, and even care if I live or die sometimes I feel. You know? Sometimes I feel that there are some people in healthcare that think a dead junkie is a better junkie. You know? I really feel that there are people that feel that way. And that's sad. We are all human beings and we all have value. (Gabriel)

Another participant talked about prioritization by social status in mainstream healthcare provision, insinuating that some people are more important than others:

> But I find in the general healthcare system, they classify people. First off, and they really classify you if you have more than one or two strikes that are different, i.e. if you are on ODSP [Ontario Disability Support Program], addicted to opiates, a bit of an alcoholic, things like that, they are saying oh well, [...]let's get to the important people first and then we will get to him. (Demarcus)

Conversely, interactions between HAMSMaRT and participants were characterized by feelings of being treated as a human being with (equal) value. They described being engaged with respect, dignity, honesty, and genuine care. One participant described their experience with HAMSMaRT:

> There's not another doctor that I've ever met that will go to the lengths that HAMSMaRT does to try to save the people at the bottom of the rungs in society. And there are some people in the bottom of the rungs that have real value, that have real things to offer society. And that's what most people don't realize. We're not all pieces of crap. We're not all looking to hurt people and take from society. We ended up there through one situation or another, you know? We all have our own stories to tell about how we ended

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> up there. But I have met so many addicts in my experience that have bigger hearts than anybody I've ever met. And have more to offer society than a lot of people. If only someone showed them that they had value. If only someone cared for them, because they're dying out there. People who, if they really felt that somebody cared, that somebody was there for them, you know, it would make such a difference. And I think that's where HAMSMaRT comes in. (Gabriel)

Patients repeatedly described that working with providers who saw them as deserving affirmed or unearthed a belief in themselves that provided them with the will to keep going and to try to heal:

> I finally started advocating for myself. I was tired. I lost everything. And then I didn't see anybody offer me a way out. So I just thought more of the status quo. And so when you have people, like those doctors, [the HAMSMaRT doctor], I came out of the hospital the last time feeling like I have a plan with hope again. (Greta)

This humanizing approach to care, explicitly driven by the ethic that *people deserve care* was described as a way in which the patient was taken from the margins to the centre of their own care.

**From the margins to the centre**

This theme represents the participants' transformative experience of moving from the mainstream system's heretofore unrealized tenet of patient-centred care into a concrete practice of being the focus of their own care. This theme represents qualities of patient-centred and patient-focused care that are baked into HAMSMaRT and tethered to the previous theme (*people deserve care*).

While patient-centred care was recognized by participants as a rhetorical hallmark of the Ontario and Canadian mainstream healthcare systems writ large, it rarely characterized their experiences when accessing care. Over and over, participants described a throughline of their experiences as being judged, ignored, disregarded, discounted, excluded and silenced, in both hospital- and office-based care settings. Rowan summarized their experience:

> They just think that you can't do things. But the thing is that I can do a lot. I can't do everything. But I was in control of my own life and then other people were treating me like a child. And that's the way I felt at the doctors. I was being treated like a child. (Rowan)

Participants, often quite generously, attributed this decentering and patronizing behaviour on the part of providers to several organizational issues in the healthcare system, including heavy patient loads and provider fatigue. They primarily experienced it however, as a powerplay that elevated the physician at their own expense. Greta said:

> And I lost all trust in doctors. I lost all hope that I had. Not because they couldn't be good doctors, but it's…I'm the hero in this story too. You know what I mean? But they played God. (Greta)

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Participants repeatedly asserted that healthcare providers didn't have a monopoly on health knowledge:

> Just because we don't have a medical license, doesn't mean we don't know what's going on with our own bodies. We're the first person who knows what's going on with us. (Freya)

Centering the patient meant dissolving the well ingrained provider-patient (knowledge) hierarchy; recognizing and acting on the intelligence and experiential expertise that the patient brought to the table when making decisions about care. When this expertise is listened to, appreciated and worked with, shared decision making is realized. True to power-sharing is the notion that the provider and patient were equal in the relationship:

> [The HAMSMaRT doctor] doesn't act like he's saving me, and that's a huge difference, because I get to be a person and I get to be an expert on my own care. And so we can work together. And to me that is what I lost with everybody else. (Greta)

This kind of power sharing depends on provider affirmation of patient autonomy. Genuine respect for patient autonomy was experienced by patients as being listened to and believed. Believing and centering patients as experts in their own health experiences led to a bi-directional cycle of truth and trust previously unenjoyed. This power sharing enhanced the provider's ability to help and the patient's ability to heal. Greta continued:

> If I didn't have this…because as I said, I had lost all hope, all belief. I thought there wasn't any hope. So when I finally had people working for me, then it felt like…somebody is working with me and I will work with them. Yeah! We have hope now that I can get out of this mess. And I can have a future. (Greta)

These mutually reinforcing orientations to patient care of deserving and centering allowed for new and different access to care systems to which patients were at best, reticent about and at worst, deliberately avoiding.

**Improved and different access to the system**

This theme describes the well-known ways in which mobile, flexible, on call, health services are necessary to increase access to care. Importantly, however, the theme also elucidates how the HAMSMaRT model provides *improved and different* access to the wider healthcare system.

For all of the participants, logistical barriers to accessing care in the mainstream system were a major roadblock to improving their health. Patients described inaccessible offices, inflexible hours, difficulties navigating the system and complex and competing priorities in a provider-centred system that refused to recognize or address all of the barriers it erected:

> And I tried explaining it to them over the phone. I said 'I can't get out. I'm housebound.' 'Oh well, you have to come down and get these.' And I said, 'you want me to come all the way down just to pick up papers? It's not to see a doctor?' And she said 'yeah.' (Rowan)

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Unsurprisingly, participants were extremely appreciative of HAMSMaRT's outreach model, which included ready access to physician support by phone, home/out of office visits and flexible scheduling. These "above and beyond" measures were viewed as a tangible enactment of the two previous themes:

> It helps because like I already said, it makes you feel important. It makes you feel special for one. So right away, you feel part of and willing to go and do whatever is required to go that extra mile to help these people, because they are coming all the way to my house. I'll certainly do what I can to help. If they're going to help me like this, then I'll help them help me. (Charlie)

Improved and different access, sometimes translated into less unnecessary use of health systems. Patients described the ways in which access to HAMSMaRT services meant they could stay out of the resource intensive emergency room, where previously (though they didn't want to) they had no choice but to go for care:

> It's incredible to have a doctor care for you and you can just text him and he's like OK, he calls the pharmacy. Or OK, I've got this going for you. Like [what happens when you start to develop an infection] Friday at 5 o'clock? Like go to the ER. And then you go through the whole process all over again. But if you have a doctor on hand like [the HAMSMaRT doctor], there's so many times when I've just called him and he's like, OK, I'm putting in something, a [prescription] or something like that. He's saved me so many times from having to go to the ER. (Nola)

Just as patients were moved by HAMSMaRT providers' decisions not to leverage their power against them, they were compelled by the way HAMSMaRT providers wielded their power *for* them; and sometimes miffed that it worked! In several instances, participants described scenarios that took the HAMSMaRT doctor's power as physician to communicate the patient's expertise, which led to care access:

> And all I called was [the HAMSMaRT doctor] and he called the [emergency room] doctor and boom I was in. It was…in a way it was frustrating, but in a way I was so relieved, you know? It was like a double-edged sword. It was like you fucking bastards. Pardon my language. But really that's what I thought. You bastards. Like this is my third visit in a week and all it took was one call from [the HAMSMaRT doctor]. OK, this patient has this, this, this, which I told them I had, which I told them I thought I had. And he repeated every single thing I said, probably to the tee and they listened to him and not to me. You know what I mean? That's not fair, you know? And I even said to him, what did you say to them? And he said, 'pretty much what you said.' He's like, 'yeah I know, it's OK. One problem at a time Freya', that's what he said, 'one problem at a time.' (Freya)

Importantly, this improved and different access also meant that patients who had previously struggled to stay in the hospital (for the maltreatment they had become so accustomed to) now could. This participant shared how their involvement with HAMSMaRT changed their access to the mainstream healthcare system:

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> In hospitals, I've always been treated differently than other patients because I have an addiction. And I don't think it's fair that I should be left to suffer in pain. I have pain issues and significant pain issues that are well documented and all verified through imaging and things like that. And since I've been dealing with HAMSMaRT [...], when I'm in the hospital, I feel like I'm treated differently now, right? Because [the HAMSMaRT doctor] always has some involvement in my care [...]. So when it comes to my pain issues and things like that, they try their best to deal with it. And I've never felt like any healthcare institution has ever tried their best on my behalf. And I feel that now. And I truly believe it's because of the involvement of HAMSMaRT. (Gabriel)

Finally, some participants described a renewed trust in possibilities of healthcare, stemming from the advocacy efforts of HAMSMaRT:

> Well working with [the HAMSMaRT doctor] made me come to terms of learning to trust doctors more than what I did, because I never really had any doctors that I wanted to see. If I was sick I dealt with it. And then something like this happens. So for that year that I had the infection, it was like I'm going to conquer this, I'm going to kill it. No two ways about it. Nobody is taking my leg or whatever. And then it so happens that the inevitable happens. Maybe I should listen to doctors a lot more. For me that's my learning experience. Now I kind of have to trust doctors and nurses more. If they say well maybe you should do this, then that's what I'm going to do. (Marlow)

These tangible and behind the scenes strategies alike were described by participants as helping them access care, leading to improvement in health, i.e. it worked!

**It works!**

For many people accessing a publicly funded healthcare system, the answer to the question of "how do you know you got good care?" takes for granted that, to the extent possible, the healthcare improved the person's health. Participant responses to this question were simple, humble and profound. Their responses spoke to how, when the three themes are brought to life, the model of care (i.e., HAMSMaRT) works. Startlingly, participants described having health improvements as the way they knew they were getting good care:

> Just seeing results, seeing the results of me getting better is proof in itself that I know that what they are doing is working. (Isla)

Freya also felt "better" since being involved with HAMSMaRT. Demarcus told us:

> There is no doubt. 100%. Because it was constant care. Difference in between waiting until I got sick and then going, then acting or reacting to that. As opposed to acting and the outcome being instead gratifying. Yeah. I felt much more at ease knowing that I could talk to him and be pointed in the right direction. (Demarcus)

Again, participants drew conclusions about their success with HAMSMaRT by drawing on, and comparing to, their experiences with the provider-centred health care system:

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> And you know, I had lost 100lbs since [major life event]. Since I've actually been getting what I think is quality healthcare, I've gained 45 of that back. Even though I was still using, I've had people say wow you look better than you've looked since [that major life event]. And I even feel it. I feel better. I look better. I'm more engaged in life. I care more about my life now. So those are the things that I think prove to me that my healthcare is better now than it was before. (Gabriel)

Participants spoke about hope and engagement in life as outcomes of their involvement with HAMSMaRT. Rowan described the profound impact of the simplicity of the HAMSMaRT approach:

> And [the HAMSMaRT doctor] came down and talked to me about stuff, and I [...] actually had given up on living. And he sat and talked to me, and said don't give up. Let's try this, we'll do this, we'll work on this. And he was giving me all these other ideas where when my family doctor dropped me and my liver doctor wasn't doing her job properly, I had just given up. I just wanted to curl up and die. And he got me back into wanting to fight to live. So that's why I'm still here. (Rowan)

Some participants expressed optimism that HAMSMaRT could lead to change in the system through replication and scaling up:

> It's amazing. You guys are doing something…I don't know what the word is for it. Like um…ground changing, or groundbreaking. Really. If more people can have this, it's going to change the way they feel about doctors and medicine. You guys really helped me. (Freya)

There was even a glimpse of restored faith in the possibility of healthcare that heals - "I actually believe now in care [...] and I just love not being sick anymore." (Isla)

In an increasingly technocratic, regimented and strained healthcare system it's impossible to miss the simplicity of what patients have here described as setting their experiences apart from those of the larger healthcare system.

**It's so simple**

There was a tone to the interviews that speaks to the simplicity of what participants viewed as requisite to a healing process. One keen and insightful participant summed it up very succinctly:

> It really is [that simple] and I don't see why it seems so hard sometimes in the hospitals. Just treat a person as a person. That's the biggest thing that could be adopted from HAMSMaRT to the healthcare system overall. (Gabriel)

Isla brought this theme of simplicity into stark reveal describing her perception of a shift in her care since working with HAMSMaRT. She said that it was the likelihood that she wouldn't be treated "like shit" that enabled her to seek the care she needed. It doesn't get much simpler than that.

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For our team, many of the strategies participants described are things we already know improve access and quality of care. One participant with extensive experience as an inpatient described a small interaction that stood out from all her time spent in hospital:

> I moved to the B wing after the E wing, and the nurse came in and I expected something. So I was like, oh, did you need me to sign something or did you need something? She goes, no I'm just coming to say hi and tell you that I'm your nurse and my name is so-and-so. And she left. And I was like holy crap. That was like…that made me feel so good and it was 2 seconds…I think that's what makes it so frustrating, is that there is not much to it. (Nola)

Here a two second interaction made the difference. Simple.

**DISCUSSION**

Our study explored the experiences of people involved in HAMSMaRT in the context of their access to and quality of care within the overall healthcare system. Our findings provide evidence that HAMSMaRT brings to life the principles that people deserve care and should be at the centre of it, leading to improved and different access to the system. When these three things are enacted, the model of care (HAMSMaRT) works. The profundity and simplicity of what patients described as quality care as realized through HAMSMaRT, and how elusive it was in the mainstream healthcare system, should give us all pause as health providers.

Our findings corroborate those of Wen and colleagues'[19] exploration of the dehumanization of people experiencing homeless by the healthcare system. They frame patient experiences as welcoming versus unwelcoming, noting that the latter's stigmatizing ethic, like in our findings of patient experiences in the mainstream health system, leads to system aversion. Our findings also parallel those of Bouchelle et al.'s[20] exploration of the experiences of medically vulnerable people accessing a mobile health van in Boston. Bouchelle et al. found that in addition to accessible communication styles, a diverse and knowledgeable workforce, and conveniently located services, a culture of respect and dignity aboard the outreach clinic was central in facilitating access to service.

Our findings also contribute to the growing evidence that mobile health clinics are effective in improving health outcomes of equity deserving people.[6,8,9] They further contribute to the small body of qualitative evidence for the effectiveness of mobile health clinics that serve people who are deprived of housing.[3] While recent qualitative work[1,19,20] explored why people use a mobile health clinic (accessing basic necessities, convenience, friendly atmosphere), our findings probe *what* it is about the model that works. Our findings describe the nuances of quality care and help to elucidate the *what* and the *how* behind the quantitative evidence of the effectiveness of mobile health clinics. In essence, our findings flesh out and affirm Wen et al.'s[19] suggestion that "the provision of effective care may be tied to the ability to create a welcoming environment."

Research about care of equity deserving populations primarily directs its gaze at either the patients of, or providers to, the population in question. The sizable body of work around patient barriers to and experiences of health care is congruent with our findings that stigma and discrimination are major deterrents to care and barriers to improved health outcomes.[21-23] There

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is a smaller body of work on the experiences of providers caring for equity deserving populations which enumerates the difficulties of providing welcoming, high-quality care within the confines of the provider-centred health system; these difficulties include providing humanized service in a stigmatizing health care milieu.[24-27] There are some efforts described in the literature to develop methods for combating the deterring stigmatizing nature of health systems[28-30]; however, there is little work done to excavate what undergirds such stigmatizing care delivery. Our findings and the existing literature demonstrate that there is a disjoint between the widely adopted rhetoric of patient-centred care and the actual practice by a critical mass of providers. Exploring this, perhaps through the perceptions and experiences of providers in the mainstream healthcare system, is an area of study rife with transformational potential.

A few caveats should be acknowledged. Our findings come from a group of participants who were involved with one type of mobile health clinic. Although the goal of qualitative research is not to generalize, we provide enough rich description to contextualize both the sample and HAMSMaRT for transferability of our findings to similar contexts. There may be contextual factors like population-level characteristics (e.g., racial or ethnic background, language) or system-wide policies or funding structures that make transferability difficult. Additionally, the constitution and size of our sample precluded us taking intersectional approach to understanding the layered stigma (and multi-stigma), discrimination and racism meted out by the health system. Also missing is the healthcare provider perspective; why might this model work for patients from the viewpoint of the provider?

We share these findings, lauding the HAMSMaRT model, with humility and in deference to the brilliance of the patients with whom we work. While we hope that the insights shared by participants will be taken up by others striving to provide better care, we also commit to implementing these findings in our own growing and changing organization. Since the time of data collection in 2018 we continue to bridge the gap between the community and hospital care. We have secured semi-stable funding, expanded and consolidated our services through a formal partnership with a user-led harm reduction group in the city, established a multi-site safer supply program for people using opioids, incorporated psychiatry and primary care into our clinical model and expanded our organizational team. We strive to extrapolate the lessons learned from these descriptions of the one-on-one patient interactions to our own HAMSMaRT "health system"; we take our lead as a healthcare organization from our patients and the community to which we all belong. All of our work begins from the principle that people deserve care that centres them, which allows us to provide improved and different access to healthcare - it works and it is that simple.

## CONTRIBUTORSHIP STATEMENT

LN and TO were responsible for research idea conception, methodology planning and participant recruitment. LN was responsible data collection oversight and coding. LN and LL were responsible for data analysis. LN, LL and TO all contributed to data interpretation and were engaged in the reflexive practice in data analysis. LN, LL and TO contributed to report writing and knowledge translation activities.

## ACKNOWLEDGEMENTS

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The authors wish to thank and acknowledge, first and foremost the HAMSMaRT patients and participants who have shared their lives and experiences with us as providers and researchers. We hope that this paper does your ideas and insights justice. We would also like to thank Dr. Sheiry Dhillon for her input into the early phases of the overall project to develop an evaluation tool for mobile outreach clinics. Thank you to Jane Tooley and Jesse Bauman for conducting some of the interviews in this project. Thank you also to Dr. Nicole Buchanan for her contributions to the background research for the project.

**COMPETEING INTERESTS**

We have no competing interests or conflicts of interests to declare.

**FUNDING STATEMENT**

This work was not funded.

**DATA SHARING STATEMENT**

Deidentified data will be shared upon responsible request by contacting the corresponding author.

**ETHICS APPROVAL**

Ethics approval for this project was received through the Hamilton-integrated Research Ethics Board (Project #4500).

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## REFERENCES

1 Whelan C, Chambers C, Chan M, Thomas S, Ramos G, Hwang SW. Why do homeless people use a mobile health unit in a country with universal health care?. *J Prim Care Community Health* 2010;1(2):78-82. https://doi.org/10.1177/2150131910372233

2 Giesbrecht M, Stajduhar KI, Mollison A, Pauly B, Reimer-Kirkham S, McNeil R, Wallace B, Dosani N, Rose C. Hospitals, clinics, and palliative care units: Place-based experiences of formal healthcare settings by people experiencing structural vulnerability at the end-of-life. *Health Place* 2018;53:43-51. https://doi.org/10.1016/j.healthplace.2018.06.005

3 Harris M. Normalised pain and severe health care delay among people who inject drugs in London: Adapting cultural safety principles to promote care. *Soc Sci Med* 2020;260:113183. https://doi.org/10.1016/j.socscimed.2020.113183

4 McNeil R, Small W, Wood E, Kerr T. Hospitals as a 'risk environment': an ethno-epidemiological study of voluntary and involuntary discharge from hospital against medical advice among people who inject drugs. *Soc Sci Med* 2014;105:59-66. https://doi.org/10.1016/j.socscimed.2014.01.010

5 Shortt SE, Hwang S, Stuart H, Bedore M, Zurba N, Darling M. Delivering primary care to homeless persons: a policy analysis approach to evaluating the options. *Healthc Policy* 2008;4(1):108.

6 Yu SW, Hill C, Ricks ML, Bennet J, Oriol NE. The scope and impact of mobile health clinics in the United States: a literature review. *Int J for Equity Health* 2017;16(1):1-12. https://doi.org/10.1186/s12939-017-0671-2

7 Oriol NE, Cote PJ, Vavasis AP, Bennet J, DeLorenzo D, Blanc P, Kohane I. Calculating the return on investment of mobile healthcare. *BMC Med* 2009;7(1):1-6.

8 Egwu, E. Mobile health clinic as a medium for reducing health disparities in underserved populations. Dissertation Georgia State University 2019. https://scholarworks.gsu.edu/nursing_dnpprojects/15

9 Jimenez A. The use of mobile healthcare clinics to expand access to underserved populations: a rapid review. Undergraduate honors thesis Central Washington University 2019 https://digitalcommons.cwu.edu/undergrad_hontheses/14

10 Liamputtong, P.  Qualitative Research Methods, 4th Ed. Melbourne: Oxford University Press 2013.

11 Patton MQ. Qualitative Research and Evaluation Methods, 3rd Ed. Thousand Oaks, CA: Sage 2002.

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12 Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qual Res Sport Exer Health* 2019; 13:1-16.

13 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psych* 2006;*3:* 77-101. https://doi.org/10.1191/1478088706qp063oa

14 Braun, V, Clarke, V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exer Health* 2019;*11*(4): 589-597.

15 Morgan DL. Pragmatism as a paradigm for social research. *Qual Inq* 2014;20:1045-1053. https://doi.org/10.1177/1077800413513733

16 Lincoln YS, Guba EG. But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New Dir Eval* 1989; 30:73-84.

17 Tracy SJ. Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. *Qual Inq* 2010;16(10): 837-851. https://doi.org/10.1177/1077800410383121

18 Patton MQ. Enhancing the quality and credibility of qualitative analysis. *Health Serv Res* 1999;34:1189-1208.

19 Wen CK, Hudak, PL, Hwang SW. Homeless people's perceptions of welcomeness and unwelcomeness in healthcare encounters. *J Gen Intern Med* 2007;22:1011-1017.

20 Bouchelle Z, Rawlins Y, Hill C, Bennet J, Perez LX, Oriol N. Preventative health, diversity, and inclusion: a qualitative study of client experience aboard a mobile health clinic in Boston, Massachusetts. *Int J Equity Health* 2007;16:191. https://doi.org/10.1186/s12939-017-0688-6

21 Kalich A, Heinemann L, Ghahari SA. Scoping review of immigrant experience of health care access barriers in Canada. *J Immigr Minor Health* 2016;18:697-709. https://doi.org/10.1007/s10903-015-0237-6

22 Ramsay N, Hossain R, Moore M, Milo M, Brown A. Health care while homeless: barriers, facilitators, and the lived experiences of homeless individuals accessing health care in a Canadian regional municipality. *Qual Health Res* 2019;29(13):1839-1849. https://doi.org/10.1177/1049732319829434

23 Monchalin, R, Smylie J, Nowgesic E. "I Guess I Shouldn't Come Back Here":racism and discrimination as a barrier to accessing health and social services for urban Métis women in Toronto, Canada. *J Racial Ethn Health Disparities* 2019;7(2)251-261. https://doi.org/10.1007/s40615-019-00653-1

24 McKeary M, Newbold, B. Barriers to care: the challenges for Canadian refugees and their health care providers. *J Refug Stud* 2010;23(4):523-545. https://doi.org/10.1093/jrs/feq038

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25 Loignon C, Hudon C, Goulet É, Boyer S, De Laat M, Fournier N, Grabovschi C, Bush P. Perceived barriers to healthcare for persons living in poverty in Quebec, Canada: the EQUIhealThY project. *Int J Equity Health* 2015;14(1):1-11. https://doi.org/10.1186/s12939-015-0135-5

26 Campbell DJ, O'Neill BG, Gibson K, Thurston WE. Primary healthcare needs and barriers to care among Calgary's homeless populations. *BMC Fam Pract* 2015;16:1-10. https://doi.org/10.1186/s12875-015-0361-3

27 Darling EK, MacDonald T, Nussey L, Murray-Davis B, Vanstone M. Making midwifery services accessible to people of low SES: a qualitative descriptive study of the barriers faced by midwives in Ontario. *Can J Midwif Res Pr* 2020;19(2):1-13.

28 Stuart H, Chen SP, Christie R, Dobson K, Kirsh B, Knaak S, Koller M, Krupa T, Lauria-Horner B, Luong D, Modgill G. Opening minds in Canada: targeting change. *Can J Psychiatry* 2014;59(suppl):13-18. https://doi.org/10.1177/070674371405901S05

29 Stuart H. Managing the stigma of opioid use. *Healthcare Management Forum* 2019;32(2):78-83. https://doi.org/10.1177/0840470418798658

30 Ungar T, Knaak S, Szeto AC. Theoretical and practical considerations for combating mental illness stigma in health care. *Community Ment Health J* 2016;52(3):262-71. https://doi.org/10.1007/s10597-015-9910-4

**FIGURE LEGEND**

Thematic map



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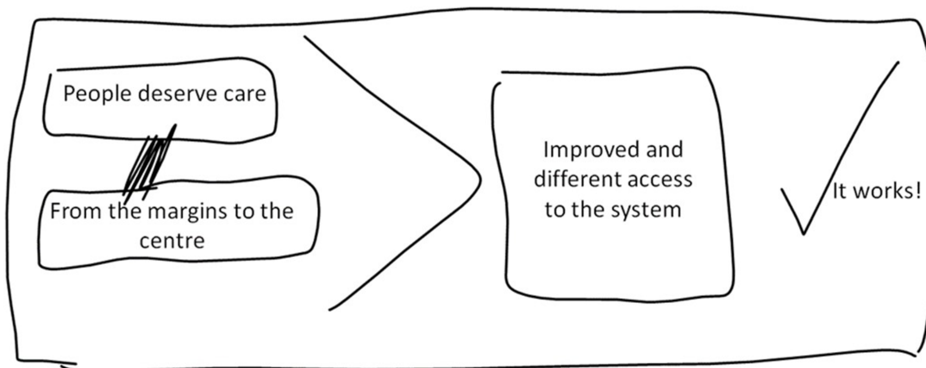


*Note.* It's so simple

Thematic map

338x190mm (96 x 96 DPI)

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**Supplementary File. Interview guide**

1. How would you describe your experiences with HAMSMaRT so far?
    a. How did you first encounter the program?
    b. How do you think HAMSMaRT's services could be improved?
        i. Was there a specific time when HAMSMaRT didn't meet your needs?
    c. What is it about HAMSMaRT that you feel would be good to apply in other similar programs?
2. Can you tell me about any experiences when you felt like you got good quality care?
    a. What changes would you like to see in the healthcare system to better serve your needs?
    b. How do you know when you've received good quality care? Some people say it's a feeling they get or it's their physical health that's improved – what is it for you?
3. Based on your experiences, what was a time when you received poor quality health care?
    a. How do you know when you've received poor quality care? Is it a feeling, a change in your physical health, or something else?
    b. Have there been times when you weren't treated well? If so, what happened that made you feel that way?
    c. Have you ever experienced stigma while getting care? If so, how did it affect the care you received?
    d. Why do you think you received poor care?
4. What barriers have you experienced in accessing health care?
    a. What was the effect of those barriers on your ability to get care?
    b. How could your access to health care have been improved?
5. In general, what qualities do you hope for in a doctor?
    a. How do you like to make decisions with your doctor?
    b. What are the most important things to you to have a good relationship with your doctor?
    c. What kind of relationship do you like to have with your doctor?
    d. What training do you think docs/HC providers are missing to provide better care?

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**Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist**

| No. Item | Guide questions/description | Reported on Page # |
|---|---|---|
| **Domain 1: Research team and reflexivity** | | |
| *Personal Characteristics* | | |
| 1. Inter viewer/facilitator | Which author/s conducted the interview or focus group? | 5 |
| 2. Credentials | What were the researcher's credentials? E.g. PhD, MD | 4-5 |
| 3. Occupation | What was their occupation at the time of the study? | 4-5 |
| 4. Gender | Was the researcher male or female? | 4-5 |
| 5. Experience and training | What experience or training did the researcher have? | 4-5 |
| *Relationship with participants* | | |
| 6. Relationship established | Was a relationship established prior to study commencement? | 5-6 |
| 7. Participant knowledge of the interviewer | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research | 6 |
| 8. Interviewer characteristics | What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | 4-5 |
| **Domain 2: study design** | | |
| *Theoretical framework* | | |
| 9. Methodological orientation and Theory | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | 6 |
| *Participant selection* | | |
| 10. Sampling | How were participants selected? e.g. purposive, convenience, consecutive, snowball | 5 |
| 11. Method of approach | How were participants approached? e.g. face-to-face, telephone, mail, email | 5 |
| 12. Sample size | How many participants were in the study? | 6 |
| 13. Non-participation | How many people refused to participate or dropped out? Reasons? | 6 |
| *Setting* | | |
| 14. Setting of data collection | Where was the data collected? e.g. home, clinic, workplace | 5-6 |
| 15. Presence of non-participants | Was anyone else present besides the participants and researchers? | 5 |

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| 16. Description of sample | What are the important characteristics of the sample? e.g. demographic data, date | 6 |
|---|---|---|
| *Data collection* | | |
| 17. Interview guide | Were questions, prompts, guides provided by the authors? Was it pilot tested? | Supplemental file |
| 18. Repeat interviews | Were repeat interviews carried out? If yes, how many? | No, no follow-up was deemed necessary |
| 19. Audio/visual recording | Did the research use audio or visual recording to collect the data? | 5 |
| 20. Field notes | Were field notes made during and/or after the interview or focus group? | No, we did not use this strategy to foster rigor, but used others |
| 21. Duration | What was the duration of the inter views or focus group? | 6 |
| 22. Data saturation | Was data saturation discussed? | 5 |
| 23. Transcripts returned | Were transcripts returned to participants for comment and/or correction? | No, we did not use this strategy to foster rigor, but used others. |
| **Domain 3: analysis and findings** | | |
| *Data analysis* | | |
| 24. Number of data coders | How many data coders coded the data? | 5-6 |
| 25. Description of the coding tree | Did authors provide a description of the coding tree? | 6 |
| 26. Derivation of themes | Were themes identified in advance or derived from the data? | 5 |
| 27. Software | What software, if applicable, was used to manage the data? | Not applicable |
| 28. Participant checking | Did participants provide feedback on the findings? | No, we did not use this strategy to foster rigor, but used others. |
| *Reporting* | | |
| 29. Quotations presented | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number | 6-13 |
| 30. Data and findings consistent | Was there consistency between the data presented and the findings? | 6-13 |
| 31. Clarity of major themes | Were major themes clearly presented in the findings? | 6-13 |
| 32. Clarity of minor themes | Is there a description of diverse cases or discussion of minor themes? | Not applicable; did not emerge in our analysis |

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