Recovery Science and Harm Reduction Reading Group

04/18/2024

**Meeting summary**:

This week’s reading group discussed the “makeshift medicine framework” – a group of concepts that describe how people take care of themselves and manage their healthcare needs when they cannot access formalized healthcare systems (e.g., hospitals, clinics). We were joined by the creator of this framework, Pat Kelly, who researches how people make medical choices and how people get medical care outside these formal systems (for example, use social systems to get medical care supplies or services). Pat discussed his prior research experiences where he found many people don’t get the help they need from the formal healthcare system. When people face big challenges in accessing formal care from doctors, often, it can be a logical choice to use resources in their community to meet their needs (e.g., getting medication from peers). Threats to healthcare access have continued to change and so have the ways people meet their healthcare needs (e.g., increased use of xylazine leads to more wounds which requires the creation of nonmedical systems to care for these wounds). Stigma is a major barrier to accessing medical care for people who use drugs. Other barriers also make people unwilling to go to formal healthcare systems, like doctors providing too low doses of medications to treat opioid use disorder (e.g., methadone, buprenorphine), which can lead to faster withdrawal symptoms and make people less likely to return to the formal healthcare system. The group discussed the importance of supporting people’s autonomy to make their own healthcare decisions (“their body, their choice”) and, if they choose to, providing them with pathways to care in the formal healthcare system with reduced barriers (for example, use of peer recovery coaches to discuss healthcare services and providers or potentially to provide wound care products or services).

**Please find the full meeting notes below**:

Siena introduced the guest speaker, Pat Kelly, PhD student at Brown, who conducts research on how people engage in medical decision-making, and how people use extra-medical care systems (e.g., relying on social systems to get medical care) when formalized healthcare systems (e.g., hospitals, clinics) are not accessible.

Siena described the article for this week on the makeshift medicine framework.

Pat gave the group an introduction to the makeshift medicine framework from his own lens, informed by his life experiences and academic and research interests. Pat discussed his prior research experiences where he found significant gaps in the healthcare system. When they face big challenges to accessing formal care from doctors, often, it can be a rational choice to use resources in their community to meet their needs (e.g., getting hormones from peers or other community members) and face big challenges to accessing formal care from doctors.

Since Pat developed the framework, Pat has been working on creating an academic course that described how people have historically used non-formalized medical care systems.

Threats to healthcare access have continued to evolve, as have the responses people use to meet their healthcare needs.

Communities have practice collective care too, to make sure that other community members get healthcare. For example, drug user unions in Vancouver, where individuals who use drugs supported each other to prevent overdose (e.g., created nonformal overdose prevention sites).

All of these challenges in the space of harm reduction and recovery science meet at the community. Community will always be present and forceful for these challenges to healthcare.

It is also rooted in that people have a fundamental right to do what they want with their body. Pat has talked with surgeons who have said that people have accessed medical care in makeshift settings that have complicated their ability to access formal medical care later. It is complex and there is a balance. People are doing the best that they can, and we should listen to community to meet their needs.

How can we, as practitioners, make it easier for people to access medical care in super low barrier ways? Syringe service programs, wound care clinics, training peers in wound care practices.

Give agency and make sure there is a path to care; don’t be patronizing for that.

How do you document makeshift medicine for the purposes of research? Pat has been mindful of this… this is an underground network of support where people are meeting their healthcare needs. Should we be documenting this? To not expose people.

The group discussion then opened up.

One attendee, a clinical social worker in Rhode Island, shared a previous experience where she worked with someone with addiction who was hesitant to receive care from the formal medical system because he knew he would face barriers. House of Hope has providers who go into the community to provide medical care, which is great. Hears of peer recovery coaches who engage in wound care treatment and it seems to be going well (providing mutual aid, need enough supplies to do so). She thinks it is a great concept and would want to be more involved with the provision of makeshift medicine to people who use drugs. Rampant stigma against people who use drugs.

Funding for wound care supplies has been a real sticking point for some of these wound care supplies. Who pays? How frequently are the supplies needed? This is an example of a structural factor that might inhibit this care.

Also, in addition to stigma, there is also the issue of lag between medical response to fentanyl wave to withdrawal. Providers may not be adequately dosing people so that they face withdrawal symptoms more quickly. This contributes to people leaving the medical system. And some people don’t want to initiate MOUD. Safe supply of opioids or provision of opioids is still radical, in medical settings/hospitals. Sometimes people will take drugs into the hospital to make sure that they can physically stay in the hospital during that time. Another example of where the formalized medical system will keep pushing people out.

Where will makeshift medicine go as the world and drug use evolves?

Pat discussed how he plans to investigate the use of xylazine, and will conduct interviews with people who use xylazine and practice management of care. His project will also use “natural language processing” to tag instances of xylazine use. The formalized medical care system has continued to lag and algorithms need to be trained; once done, we can use this roadmap to better respond to future drug trends and related consequences. This is one example.

Pat says anecdotally, yes. Sometimes the patients may not know what is happening with xylazine use, while providers can sometimes connect the dots to see trends across patients.