MENTAL HEALTH SERVICE USERS' AND CARERS' EXPERIENCES OF CANCER CARE

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No Conflicts of Interest

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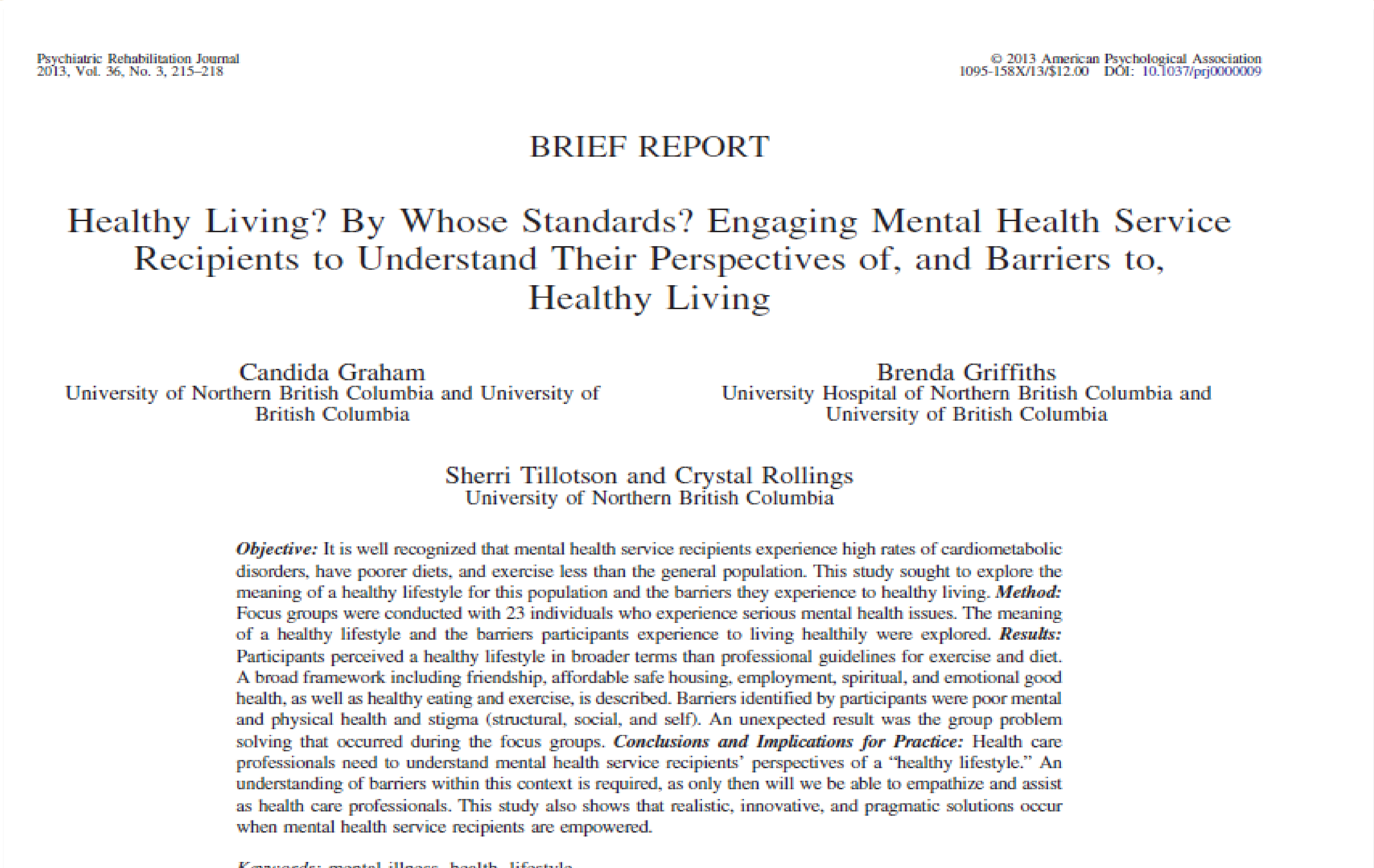
- University of Northern British Columbia
- Provincial Health Services Authority (PHSA) - BC Cancer Agency Centre for the North
- BC Schizophrenia Society (Community Partner)
- Northern Health Authority (MH & A)



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BRIEF REPORT

Healthy Living? By Whose Standards? Engaging Mental Health Service Recipients to Understand Their Perspectives of, and Barriers to, Healthy Living

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Objective: It is well recognized that mental health service recipients experience high rates of cardiometabolic disorders, have poorer diets, and exercise less than the general population. This study sought to explore the meaning of a healthy lifestyle for this population and the barriers they experience to healthy living. ***Method:*** Focus groups were conducted with 23 individuals who experience serious mental health issues. The meaning of a healthy lifestyle and the barriers participants experience to living healthily were explored. ***Results:*** Participants perceived a healthy lifestyle in broader terms than professional guidelines for exercise and diet. A broad framework including friendship, affordable safe housing, employment, spiritual, and emotional good health, as well as healthy eating and exercise, is described. Barriers identified by participants were poor mental and physical health and stigma (structural, social, and self). An unexpected result was the group problem solving that occurred during the focus groups. ***Conclusions and Implications for Practice:*** Health care professionals need to understand mental health service recipients' perspectives of a "healthy lifestyle." An understanding of barriers within this context is required, as only then will we be able to empathize and assist as health care professionals. This study also shows that realistic, innovative, and pragmatic solutions occur when mental health service recipients are empowered.

Keywords: mental illness, health, lifestyle

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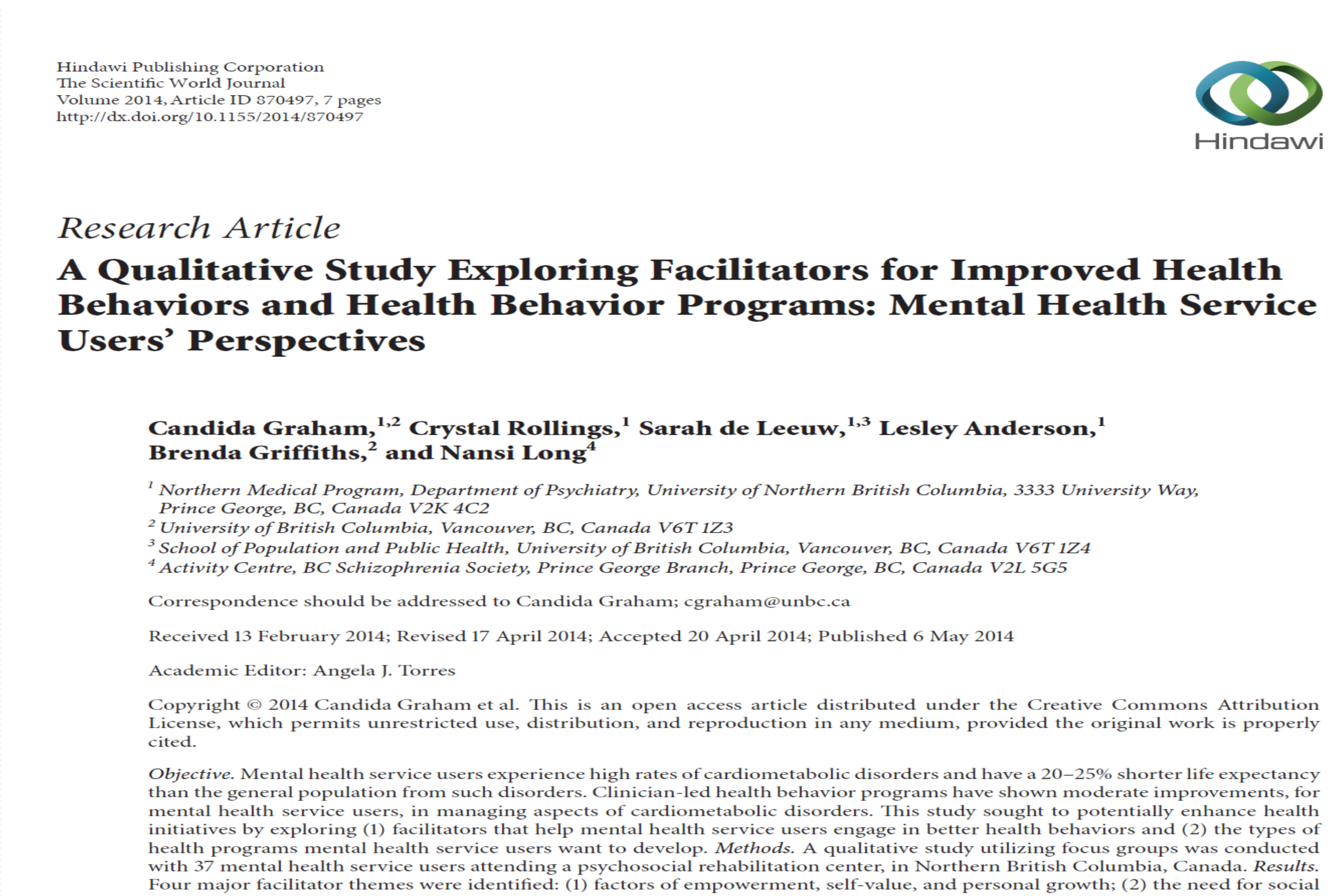

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Research Article

A Qualitative Study Exploring Facilitators for Improved Health Behaviors and Health Behavior Programs: Mental Health Service Users' Perspectives

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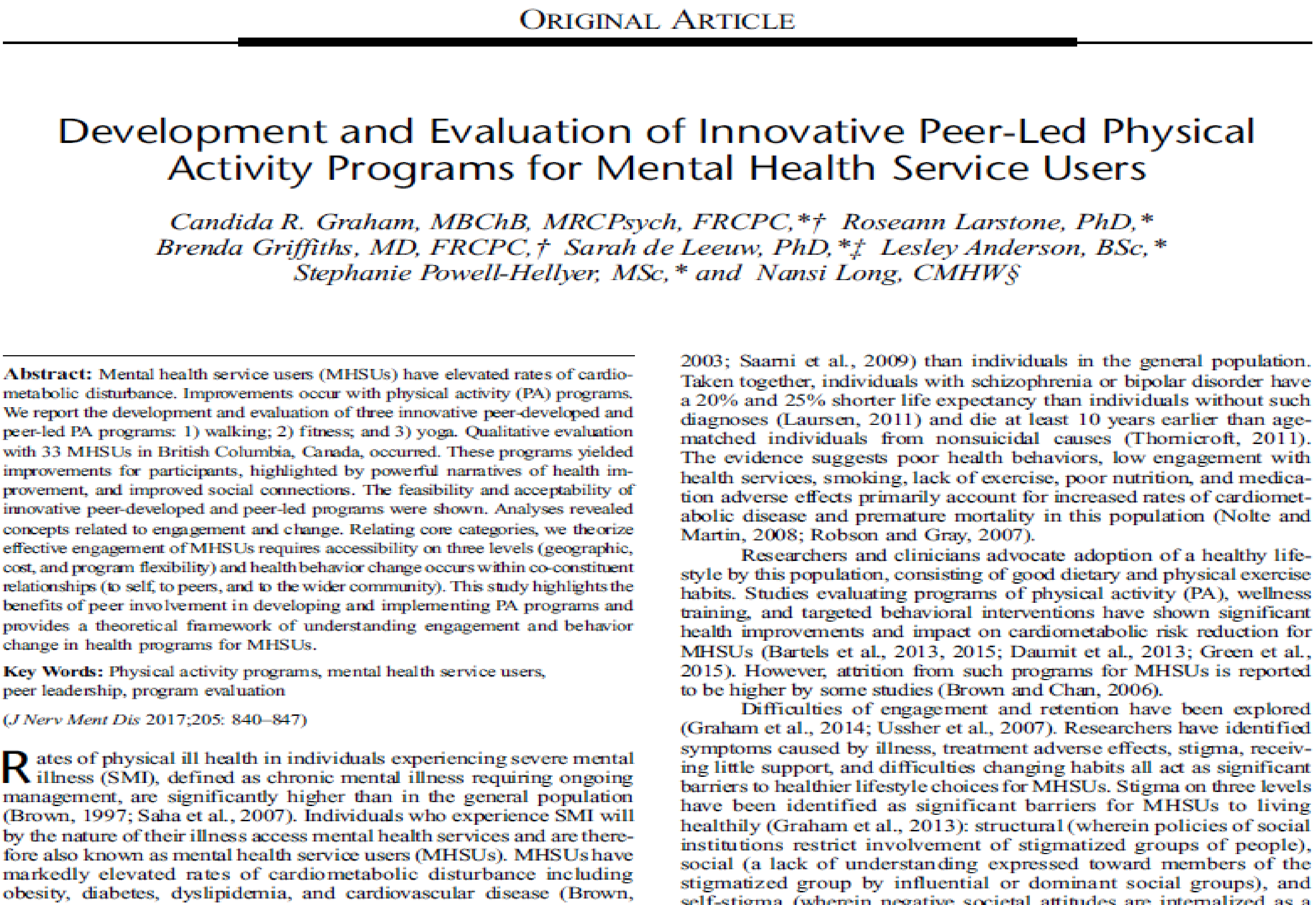
Objective. Mental health service users experience high rates of cardiometabolic disorders and have a 20–25% shorter life expectancy than the general population from such disorders. Clinician-led health behavior programs have shown moderate improvements, for mental health service users, in managing aspects of cardiometabolic disorders. This study sought to potentially enhance health initiatives by exploring (1) facilitators that help mental health service users engage in better health behaviors and (2) the types of health programs mental health service users want to develop. *Methods.* A qualitative study utilizing focus groups was conducted with 37 mental health service users attending a psychosocial rehabilitation center, in Northern British Columbia, Canada. *Results.* Four major facilitator themes were identified: (1) factors of empowerment, self-value, and personal growth; (2) the need for social



ORIGINAL ARTICLE

Development and Evaluation of Innovative Peer-Led Physical Activity Programs for Mental Health Service Users

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Abstract: Mental health service users (MHSUs) have elevated rates of cardiometabolic disturbance. Improvements occur with physical activity (PA) programs. We report the development and evaluation of three innovative peer-developed and peer-led PA programs: 1) walking; 2) fitness; and 3) yoga. Qualitative evaluation with 33 MHSUs in British Columbia, Canada, occurred. These programs yielded improvements for participants, highlighted by powerful narratives of health improvement, and improved social connections. The feasibility and acceptability of innovative peer-developed and peer-led programs were shown. Analyses revealed concepts related to engagement and change. Relating core categories, we theorize effective engagement of MHSUs requires accessibility on three levels (geographic, cost, and program flexibility) and health behavior change occurs within co-constituent relationships (to self, to peers, and to the wider community). This study highlights the benefits of peer involvement in developing and implementing PA programs and provides a theoretical framework of understanding engagement and behavior change in health programs for MHSUs.

Key Words: Physical activity programs, mental health service users, peer leadership, program evaluation

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Rates of physical ill health in individuals experiencing severe mental illness (SMI), defined as chronic mental illness requiring ongoing management, are significantly higher than in the general population (Brown, 1997; Saha et al., 2007). Individuals who experience SMI will by the nature of their illness access mental health services and are therefore also known as mental health service users (MHSUs). MHSUs have markedly elevated rates of cardiometabolic disturbance including obesity, diabetes, dyslipidemia, and cardiovascular disease (Brown, 2003; Saarni et al., 2009) than individuals in the general population. Taken together, individuals with schizophrenia or bipolar disorder have a 20% and 25% shorter life expectancy than individuals without such diagnoses (Laursen, 2011) and die at least 10 years earlier than age-matched individuals from nonsuicidal causes (Thornicroft, 2011). The evidence suggests poor health behaviors, low engagement with health services, smoking, lack of exercise, poor nutrition, and medication adverse effects primarily account for increased rates of cardiometabolic disease and premature mortality in this population (Nolte and Martin, 2008; Robson and Gray, 2007).

Researchers and clinicians advocate adoption of a healthy lifestyle by this population, consisting of good dietary and physical exercise habits. Studies evaluating programs of physical activity (PA), wellness training, and targeted behavioral interventions have shown significant health improvements and impact on cardiometabolic risk reduction for MHSUs (Bartels et al., 2013, 2015; Daumit et al., 2013; Green et al., 2015). However, attrition from such programs for MHSUs is reported to be higher by some studies (Brown and Chan, 2006).

Difficulties of engagement and retention have been explored (Graham et al., 2014; Ussher et al., 2007). Researchers have identified symptoms caused by illness, treatment adverse effects, stigma, receiving little support, and difficulties changing habits all act as significant barriers to healthier lifestyle choices for MHSUs. Stigma on three levels have been identified as significant barriers for MHSUs to living healthily (Graham et al., 2013): structural (wherein policies of social institutions restrict involvement of stigmatized groups of people), social (a lack of understanding expressed toward members of the stigmatized group by influential or dominant social groups), and self-stigma (wherein negative societal attitudes are internalized as a

BACKGROUND

Mental health service users [MHSUs] experience high rates of cancer risk and incidence (Kisely et al., 2013; Lin et al., 2013; McGinty et al., 2012)

MHSUs encounter health inequities & multiple barriers to health (Graham et al., 2013; 2014; 2017)

Cancer incidence rates have been shown to be 17% and 29% higher for all cancers in the context of SMI compared to the general population (Lin et al., 2013)

PURPOSE

No studies to date have included MHSUs’ and their informal carers’ perspectives to explore experiences of possible barriers, access and inequities to cancer care for MHSUs

Urgent need to understand barriers to begin to decrease inequities in cancer care for MHSUs

OBJECTIVES

1. To convene and mobilize key stakeholders to support engagement and connectivity

2. To generate new knowledge by exploring and gaining understanding of MHSUs’ and informal carers’ experiences and perspectives of cancer care for MHSUs

METHODS

- Grounded theory
- Participant recruitment: purposeful sampling

INCLUSION CRITERIA

I. MHSUs who:

1) are living with enduring mental illness;
2) are over the age of 19;
3) have received a cancer diagnosis in the past year;
4) are experiencing a stable mental state at the time of the study;
5) are not patients currently under the care of the Nominated Principal Investigator (NPI); and
6) are able to give informed consent.

II. Informal carers for such individuals who are:

1) over the age of 19 years; and
2) able to give informed consent.

DEMOGRAPHICS

Variable	**N=9** **n (%)**
Sex	
Female	8 (88.9%)
Male	1 (11.1%)
Participant group	
MHSUs	6 (66.7%)
Carers	3 (33.3%)
Diagnoses	
Bipolar disorder	2 (22.2%)
Depression	2 (22.2%)
Schizoaffective disorder	1 (11.1%)
Other	3 (33.3%)

INTERVIEW QUESTIONS

We would like to know about your experiences in the cancer journey since you were/the person you care for was diagnosed.

What has the experience been like?

How did you find out you / the person you care for, had cancer?
How was that experience?

What have been the areas of greatest need?

INTERVIEW QUESTIONS

What types of cancer care services have you accessed?

Are there areas of need in your care that you feel haven’t been met?

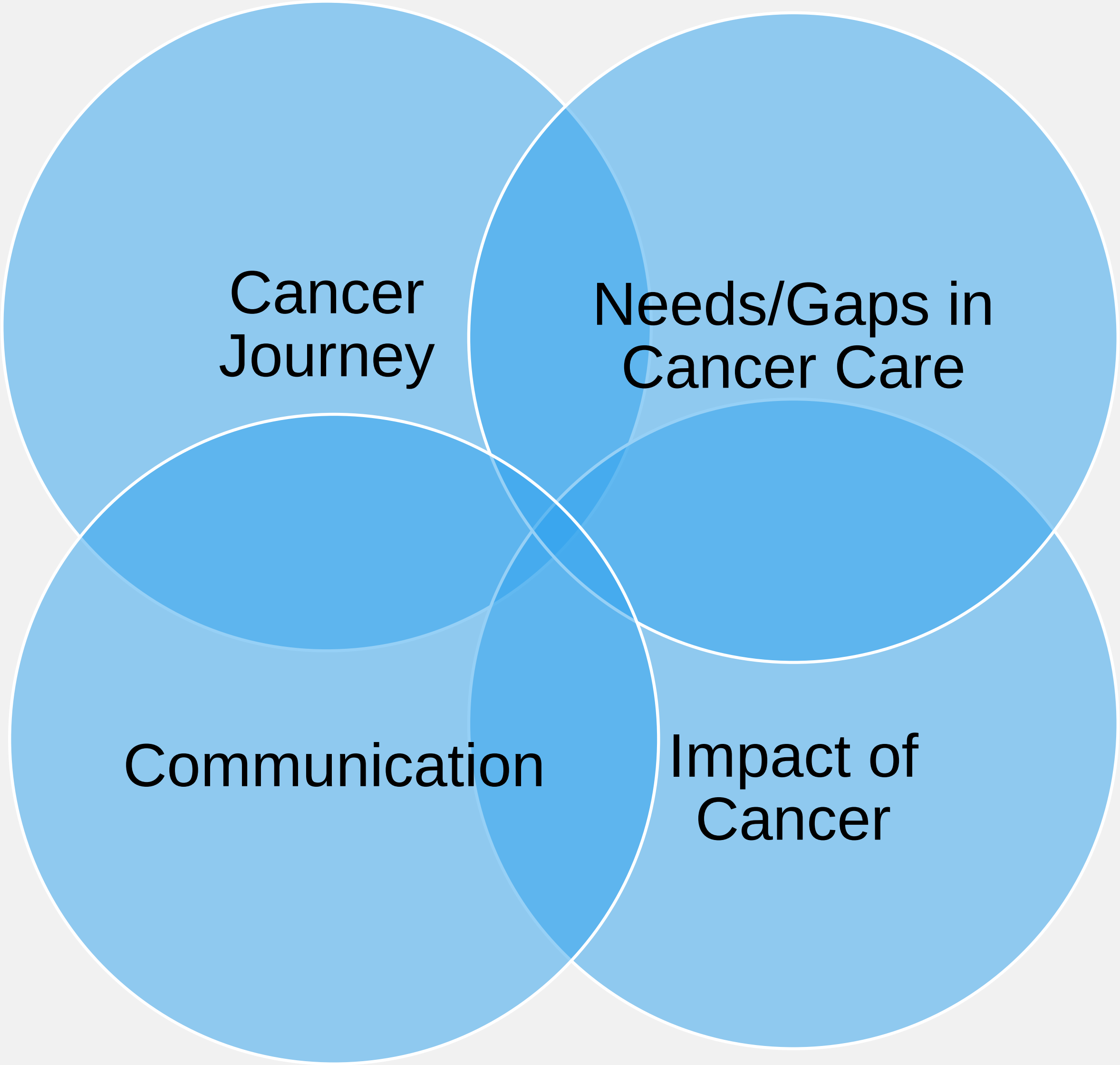
Have other supports in the local community helped you throughout the cancer journey?

Tell me about your experiences of accessing health screening for cancer.

ANALYSIS

- Grounded Theory informed thematic analysis
- Development of themes and concepts
- Iterative process

RESULTS



Cancer Journey

Needs/Gaps in Cancer Care

Communication

Impact of Cancer

Cancer Journey (MHSUs)	Positive	Negative
Exemplary quotes	“[the experience of having cancer] shows who’s there for you in your life… people are really going to fade into the background, or they’re going to choose to help you.”	“Overwhelming”
	“[The] journey was faster than I thought it was going to be”	“Isolating”
	“I think having the Cancer Agency here has made a world of difference …. I couldn’t afford it [traveling for cancer care]…”	“I didn’t expect it [the cancer diagnosis], it came out of nowhere.”
	“…my doctors were proactive.” “I knew the outcome very quickly”	[Cancer is] “a huge focus”

Cancer Journey (Carers)	Positive	Negative
Exemplary quotes	“…[we had a] fairly good experience in terms of what we were expecting versus of what we got in terms of the journey.”	“We were dropped in the middle of an ocean with no life jacket, figure it out.”
	“…now it’s kind of, trying to look at the more positive part of [the journey] and look at what the outcome can be.”	“It’s very stressful. You are expected to be nurse, caregiver, mental health supporter…”
		“The [surgery] cancellations were very stressful.”

Needs and Gaps in Cancer Care (MHSUs)	a. Financial	b. Practical
Exemplary quotes	"…without the [financial] help of my mom and dad…I would've had a hard time."	"It would be cool to have something else to help with things like maybe getting groceries. When you're just really tired you don't have the energy to go places."
	"if you don't have the money to [eat healthily] [nutritional advice for cancer patients] doesn't help."	"…sometimes you forget everything that is said so you've got someone else to help you remember stuff. You almost need a recorder for yourself"
	"…medication would be a bigger one [cost] too […] I mean usually people [doctors] just give you [a prescription] and say here buy it."	"…groceries, sometimes I need help with that…"
	"I just really can't afford to have cancer."	"I always kind of worry about losing my [mental health] worker because she's my lifeline."

Needs and Gaps in Cancer Care (MHSUs)	c. Social	d. Information/other supports
Exemplary quotes	"[an unmet need is] for people to give you space, but not too much."	"This is something I think is also underserviced is that there [are] patient supports but not so much for individual family members"
	"I sort of withdraw within myself, I don't want anybody to talk to me."	"overbooking…I think that the services are probably there…[but] I only see [my support worker] once every two or three months"
	"Just knowing that somebody's there you can talk to them even if you don't do it, the availability of it is what keeps me calm."	"more relaxation [programs] like meditation and stuff like that could maybe be a little more accessible"

Needs and Gaps in Cancer Care (Carers)	a. Financial	b. Practical
Exemplary quotes	“I can’t financially keep affording, I can’t afford to keep my home and give [them] what [they] need. So every aspect of financial, emotional, physical stress is there”	“somehow set up a system where family members could be included in teleconferences…then family members… can hear it too, instead of having to hear [medical information] from the patient who’s maybe not hearing everything”
	“[the] cost of living is pretty crazy”	“[while] recover[ing] from the surgery… it was practical, physical needs. It was going grocery shopping, it was getting medications, it was cleaning [the] house…”
	“…our main struggle is financial”	“Someone come clean my house, someone come get groceries, like I don’t have time.”

Needs and Gaps in Cancer Care (Carers)	c. Social	d. Information/other supports
Exemplary quotes	“[cancer] impacted…[the] ability to spend time with the [grand]kids because of course she wasn’t able to spend…time with [them] that she normally would…so that was a little bit of the social support that was gone”	“There is no mental health education on how to be supportive or how to just sit there and listen. People are uncomfortable with being uncomfortable. And in cancer land, you have no choice, you learn to be more comfortable in the uncomfortable”
		“I think it’s more the time restraint [for increased access to mental health services”]
		“We don’t have a support network that sets people up to go through the process as easily as possible”

Communication (MHSUs and Carers)	Positive	Negative
Exemplary quotes	“I think the doctors did their best to explain it [the cancer diagnosis] in… a little easier to grasp terms”	“I think I felt like sometimes [HCPs] were a little more on guard around me”
	“[the oncologist was] quite precise in laying out timelines and… the chances of recurrence”	“the doctor never really said ‘I’m really sorry I had to cancel this surgery or I’m sorry that that caused you anxiety’”
	“I feel at first our relationship [with mental healthcare specialist] wasn’t good but I think he’s gained a lot of respect for me. I think that’s going good”	“…they knew that I was a mental health client…did they see mental health on the chart and decide we’re just not going to deal with [me]”
	“…our family doctor is really cognizant of [mental health issues]…they asked ‘Are you doing okay? Do you need anything extra?’”	“Whackload of terminology” “when I switched from cancer care to mental [health] care, I was treated very differently.”

Impacts of Cancer	a. Physical	b. Social
Exemplary quotes	“[my family member] doesn’t realize that chemo takes a lot out of a person…”	“I find I’ve withdrawn socially after being diagnosed”
	“I found after doing chemo…I had a hard time with… concentration and attention”	“I need to socialize but…I’m so deep into my isolated thinking right now”
	“I had four months [of treatment] backtracked because of chemo burn”	“I’m quite surprised at how differently we treat people with cancer as opposed to how we treat people with mental illness…”
	“I gained [weight] I’d lost [before]”	“I’m isolating”

Impacts of Cancer	c. Mental health
Exemplary quotes	“I’m having a hard time adjusting to not being able to work… I can’t find a personal identity…”
	“I guess just that it’s an added level when you have a mental illness. [Cancer is] going to affect you differently. There’s not too many people that won’t backslide in some way or other and so they might need more medications or visits or whatever.”
	“I noticed I went back a little more in my mental health”

DISCUSSION

- First study incorporating MHSUs and informal carers' perspectives of cancer care for MHSUs

- Identified barriers include: financial barriers, practical (transportation; activities of daily living).

- Stigma emerged as a significant barrier. Education for HPCs to enhance scope of practice

LINKS TO PRACTICE

- Need for improved communication/education around screening & diagnostic tests (simple language). Write things down for patients to take with them

- Professionals anticipate and address potential effects on mental health (decrease anxiety)

- Need for education for family members re: effects of cancer and cancer treatment

LINKS TO PRACTICE

- Think about the “whole patient” and their needs beyond cancer care

- Inclusion of other HCPs and team members who are providing services ensures a consistent level of care and decreases negative impacts (mental health)

- Findings point to possible programs to improve care (peer-led model)

LIMITATIONS

- Selection bias
- Economic incentives

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REFERENCES

Graham, C., Griffiths, B., Tillotson, S., & Rollings, C. (2013). Healthy living? By whose standards? Engaging mental health service recipients to understand their perspectives of, and barriers to, healthy living. *Psychiatric Rehabilitation Journal*, *36*, 215–218.

Graham, C., Rollings, C., de Leeuw, S., Anderson, L., Griffiths, B., & Long, N. (2014). A qualitative study exploring facilitators for improved health behaviors and health behavior programs: Mental health service users' perspectives. *The Scientific World Journal,* Article ID 870497, http://dx.doi.org/10.1155/2014/870497

Graham, C., Larstone, R., Griffiths, B., Powell-Hellyer, S., de Leeuw, S., Anderson, L., & Long, N. (2017). Development and qualitative evaluation of an innovative peer-led physical activity initiative for mental health service users. *The Journal of Nervous and Mental Disease, 205,* 840-847.

Kisely, S., Crowe, E., & Lawrence, D. (2013). Cancer-related mortality in people with mental illness. *JAMA Psychiatry, 70*, 209-217.

Lichtermann, D., Ekelund, J., Pukkala, E., Tanskanen, A., & Lönngvist, J. (2001). Incidence of cancer among persons with schizophrenia and their relatives. *Archives of General Psychiatry, 58,* 573-578.

Lin, G.M., Chen, Y.J., Kuo, D.J., Jaiteh, L.E., Wu, Y.C., Lo, T.S., & Li, Y.H. (2013). Cancer incidence in patients with schizophrenia or bipolar disorder: a nationwide population-based study in Taiwan, 1997-2009. *Schizophrenia Bulletin, 39*, 407-416. doi: 10.1093/schbul/sbr162.

McGinty, E.E., Zhang, Y., Guallar, E., Ford, D.E., Steinwachs, D., Dixon, L.B., Keating, N.L., & Daumit, G.L. (2012). Cancer incidence in a sample of Maryland residents with serious mental illness. *Psychiatric Services, 63*, 714-717.