

### Editor's key points

- ▶ Substance use in pregnancy is a growing health issue worldwide across sociodemographic and geographic boundaries. Women's voices about their care are often missing from the literature. This project aimed to engage women who had accessed services from Sheway, a program for women with substance use during pregnancy, and empower them to take charge of the knowledge-generating process.
- ▶ The women, who were co-researchers on the project, described Sheway as family and mothering and recovery as a journey; they expressed challenges with transitioning out of the program; and they offered considerations for family doctors.
- ▶ The women also shared numerous ideas to improve Sheway, and 2 action projects were prioritized and implemented. Many in the group were eager to share their experience further and create dialogue and they participated in presentations to care providers.

# “People in regular society don't think you can be a good mother and have a substance use problem”

## Participatory action research with women with substance use in pregnancy

Kali Gartner MD CCFP Kelly Elliott Michelle Smith Hilary Pearson MA PhD CCC  
Georgia Hunt MD CCFP Ruth Elwood Martin MD FCFP MPH

### Abstract

**Objective** To work collaboratively with women accessing an integrated program for women with substance use in pregnancy to learn how services can be improved.

**Design** Qualitative design using focus groups within a participatory action framework.

**Setting** Sheway, a program located in the Downtown Eastside of Vancouver, BC.

**Participants** A total of 21 co-researchers who were women who had accessed Sheway services.

**Methods** Semistructured focus groups were recorded and transcribed. Data analysis was iterative and reviewed weekly with focus group members. Themes were member checked and reviewed with co-researchers. The action phase of the project involved the co-researchers presenting their main findings to the Sheway staff members. The staff and women worked collaboratively to implement client-directed changes to the program.

**Main findings** Co-researchers described Sheway as family. They expressed concern about transitioning from the program to other community services and identified stereotypes and negative treatment by health care providers as barriers to their transition out of the program. One action project developed by the co-researchers was a “transition group” where women could connect to current and former Sheway clients. The women could retain the social support they gained through Sheway while learning about other resources. The co-researchers also prioritized developing peer-to-peer mentorship to support new clients. The findings of the research were disseminated to Sheway staff, the Department of Family Practice at the University of British Columbia, and local family medicine maternity care providers with the hope of improving care for women with substance use in pregnancy.

**Conclusion** A participatory action framework allowed women to engage as co-researchers. The co-researchers emphasized the importance of relationships and a sense of family with other women as well as providers as positive aspects of their care. Women involved in this project identified negative attitudes of health care providers toward substance use in pregnancy as barriers. Co-researchers proposed transition support and peer-to-peer networking as action projects to improve their care.



## Points de repère du rédacteur

► La consommation de drogues ou d'alcool durant la grossesse constitue un problème de santé de plus en plus important dans le monde, par-delà les frontières sociodémographiques et géographiques. Il est toutefois rare que les publications traitent de l'opinion qu'ont les femmes des soins qu'elles reçoivent. Le présent projet visait à recruter des femmes inscrites à Sheway, un programme s'adressant aux femmes ayant un problème d'abus de substances durant la grossesse, et à les rendre capables de prendre en main un processus d'acquisition de connaissances.

► Les femmes, qui agissaient comme co-chercheurs dans le projet, ont décrit Sheway comme un voyage à travers la famille, le maternage et la guérison; elles ont parlé des difficultés à quitter le programme; et elles ont soulevé des matières à réflexion pour les médecins de famille.

► Les femmes ont également proposé plusieurs façons d'améliorer Sheway, et la priorité a été donnée à deux projets. Plusieurs membres du groupe avaient hâte de partager davantage leur expérience et d'engager le dialogue, et elles ont participé à des présentations offertes à des prestataires de soins.

# Les membres de la société ordinaire croient qu'il est impossible d'être une bonne mère si on a un problème de consommation de drogue ou d'alcool

## Une étude à laquelle ont participé des femmes enceintes consommant des drogues ou de l'alcool

Kali Gartner MD CCFP Kelly Elliott Michelle Smith Hilary Pearson MA PhD CCC  
Georgia Hunt MD CCFP Ruth Elwood Martin MD FCFP MPH

### Résumé

**Objectif** Travailler en collaboration avec des femmes inscrites à un programme destiné aux femmes ayant un problème d'abus de substances durant la grossesse afin d'apprendre comment ce type de service pourrait être amélioré.

**Type d'étude** Une étude qualitative ayant recours à des groupes de discussion dans le cadre d'une action participative.

**Contexte** Sheway, un programme localisé dans le quartier *Downtown Eastside* de Vancouver, en Colombie-Britannique.

**Participant** Un total de 21 femmes co-chercheurs ayant eu recours aux services du programme Sheway.

**Méthodes** Les groupes de discussion semi-structurés ont été enregistrés, pour ensuite être transcrits. L'analyse itérative des données a été révisée chaque semaine par les membres du groupe. Les thèmes ont été vérifiés par les membres et révisés avec les co-chercheurs. Durant la phase active du projet, les assistantes de recherche présentaient leurs principales observations aux chercheurs. Les membres du personnel collaboraient avec les femmes pour mettre en œuvre les changements du programme à l'intention des clientes.

**Principales observations** Les assistantes de recherche ont décrit Sheway comme une famille. Elles se sont dites inquiètes du moment où elles passeraient de ce programme à d'autres services communautaires, et ont déterminé que les stéréotypes et les traitements négatifs de la part des prestataires de soins faisaient obstacle à leur transition à l'extérieur du programme. Les co-chercheurs ont mis sur pied un projet de groupe de transition (transition group) au sein duquel les femmes pouvaient communiquer avec des clientes de Sheway, actuelles et anciennes. Les participantes pouvaient conserver le soutien reçu grâce à Sheway tout en se renseignant sur d'autres ressources. Elles pensaient aussi qu'il était prioritaire d'établir un mentorat entre pairs pour aider les nouvelles clientes. Les résultats de l'étude ont été largement communiqués aux membres du personnel de Sheway, au Département of Family Practice de l'Université de la Colombie-Britannique ainsi qu'aux responsables locaux des soins de maternité, dans l'espoir d'améliorer ainsi les soins prodigués aux femmes ayant un problème d'abus de substances durant la grossesse.

**Conclusion** Grâce au cadre d'action participative du projet, des femmes ont pu y travailler comme co-chercheurs. Ces femmes ont souligné l'importance des relations et le sentiment de former une famille avec les autres femmes et avec les soignants comme étant des aspects positifs de leurs soins. Les participantes ont précisé que les attitudes négatives de la part de prestataires de soins quant à l'abus de substances durant la grossesse constituaient un obstacle. Pour améliorer les soins, elles ont suggéré d'offrir un soutien durant la transition et de créer des réseaux de pairs.

**S**ubstance use in pregnancy is a growing health concern worldwide across socioeconomic segments of urban and rural communities.<sup>1-3</sup> Substance use in pregnancy is difficult to estimate as it might not be recognized by health care providers or reported by women. Estimates suggest 5% to 20% of women use substances during pregnancy.<sup>4-7</sup> In some communities the rates of substance use are higher. For example, a prospective cohort study of women in northern Ontario found that 28% of women used narcotics in pregnancy, and daily injection narcotic use was a common pattern.<sup>8</sup>

Many contextual factors increase risk of substance use disorders for women including past history of childhood sexual or physical abuse, violence, partners who use substances, limited family supports, homelessness, troubled relationships, unstable family of origin, low self-esteem, and mental health comorbidity.<sup>2,9</sup> Women using substances in pregnancy are particularly marginalized as a result of stigma surrounding drug and alcohol use in pregnancy and limited access to appropriate services. Women who use substances are more likely to seek care late in pregnancy or attempt to conceal drug use for fear of apprehension of their children.<sup>10</sup> It is well recognized that traditional prenatal care based on short appointments and limited psychosocial support is inadequate for this population.<sup>6,11-13</sup> Women in the Downtown Eastside (DTES) of Vancouver, BC, who are pregnant or in the postpartum period consistently report high levels of physical, emotional, and sexual abuse from various perpetrators and often have experience in foster care and unstable families of origin themselves.<sup>14</sup> In addition, Indigenous women with current or past problematic substance use also face structural racism and stigma related to Canada’s history of colonial violence.<sup>15</sup>

Comprehensive, interdisciplinary programs have been suggested as a way to provide a safe environment and services in a “one-stop shop” model.<sup>16</sup> Sheway, a Coast Salish word for growth, in Vancouver is one example of such a program.<sup>3,10,15,17,18</sup> Sheway is located in the DTES in a community with high rates of poverty, food insecurity, inadequate housing, and substance use.<sup>19</sup> This community also had a large urban Aboriginal population experiencing the intergenerational effects of Canada’s history of colonialism, residential schools, and systematic efforts to extinguish Aboriginal culture and language.<sup>20</sup> Sheway operates in a women-centred model drawing on experience from an interdisciplinary team including social work, counseling, addiction workers, nursing, early childhood development, medicine, legal support, Aboriginal cultural support, and housing advocacy.<sup>17,21,22</sup> Sheway provides daily meals in a drop-in, child-friendly space allowing women to identify the services they need.<sup>6,11,12</sup> A cohort study of integrated methadone maintenance programs for pregnant women in Canada (including Sheway) found reduction in substance use from the first visit compared with delivery,

as well as improvements in housing status, in women accessing methadone maintenance at Sheway.<sup>1</sup>

This participatory action research grew out of the experience of working with women and families at Sheway (G.H.) and women receiving care at Sheway expressing interest in providing feedback and directing change (K.E., M.S.). Previous projects at Sheway suggested incorporating feedback mechanisms for Aboriginal women to ensure they could maintain control over health services.<sup>3</sup> The aim of this study was to empower women with a history of perinatal substance use and give them the opportunity to bring their voice to clinicians and the literature with the aim of client- and patient-directed change and improved services. Ideal communication and collaboration between clients and staff has a beneficial effect on compliance and engagement, which is partly attributed to the value of empowering women to be shared participants in their treatment plan.<sup>2</sup> The objective of this project was to work collaboratively with women accessing Sheway to learn how services can be improved to meet their needs.

## — Methods —

### Participatory action research framework

This project aimed to engage women who are often marginalized and empower them to take charge of as much of the knowledge-generating process as possible.<sup>3,17,23</sup> A participatory action research methodology was selected, as this method aims to be empowering and increase the control participants have over their own lives. It is a self-reflective and action-focused methodology. Also, it closely observes power relationships with the aim of power being shared among the research team. These values are reflective of the Sheway program and the objective of the project.<sup>23</sup> A qualitative design was chosen with the aim of exploring individual and group experiences related to accessing health care services as a pregnant woman with a substance use history.<sup>24</sup>

### Sheway context and role of the researchers

As previously described, Sheway is an interdisciplinary, one-stop shop program for women with substance use in pregnancy and their children. The mean age of women accessing Sheway services is approximately 26 years old, but the age range is 14 to 55 years of age.<sup>1</sup> Women accessing Sheway consistently report challenges with adequate housing and food security. In a recent analysis of Canadian integrated care programs for pregnant women accessing methadone programs, 53% of the women from the Vancouver site were Indigenous.<sup>1</sup> This was significantly higher than the sites in Toronto, Ont, and Montreal, Que ( $P < .01$ ).<sup>1</sup> Traumatic experiences, including apprehension of an infant, partner and family violence, and homelessness or unstable housing, are frequently reported by women accessing Sheway

services.<sup>15</sup> By describing the context of the research setting, we enhance the transferability of the project findings.

The authors are a diverse group, including women who had accessed Sheway services (K.E., M.S.), a family medicine resident who completed clinical training at Sheway (K.G.), a family physician working as the medical director at Sheway (G.H.), and experts in participatory research and qualitative research design (R.E.M., H.P.). Women participating in focus groups were all involved as co-researchers in the project, thus ensuring credibility of the findings.

## Recruitment

We recruited current or past Sheway clients as co-researchers. We selected the word *co-researchers* rather than *participants* or *subjects* to emphasize the participatory design. We excluded partners, family members, or service providers, as we wanted to ensure a safe space where the voices of women could be heard. We invited women to take part in a participatory action project, Empowering Mothers, on how Sheway could be improved. We explained that participatory research is carried out by a group of people who have experience, ideas, and expertise to share who then make a plan together of what to do next. Women were recruited to participate through purposive sampling using posters at the Sheway drop-in, and staff invited women personally.<sup>24</sup> Women were also encouraged to invite their peers (snowball sampling).<sup>24</sup> This sample of women accessing Sheway services included those new to the program and those who had been attending for a number of years. The co-researchers attending focus groups were representative of the women accessing Sheway services.

Written informed consent was obtained individually before the focus group. Women could withdraw their consent at any time. Only one woman left a focus group early; she had to attend to another commitment. While space and honoraria funding imposed limits on the number of participants, no voices were systematically excluded. Women and their children first shared a catered meal and child care was provided in a separate area during the focus groups. The women received an honorarium (\$20) and a transit ticket before the start of the focus group for their participation.

## Ethics

Ethical approval was granted by the University of British Columbia Behavioural Research Ethics Board and the Vancouver Coastal Health Research Ethics Committee.

## Focus groups

Focus groups were selected to allow for the maximum number of participants and to foster a setting where women could come together in a positive environment to share their views. A family medicine resident facilitated 4 weekly focus groups (K.G.). One Sheway staff

physician was involved in child care in a separate part of the building and was not involved in focus group discussions to allow the women to express their views in a confidential environment.

## Data collection

Focus groups were audiorecorded (with consent) and transcribed verbatim with identifying information removed. Transcription was performed at the end of each group and checked for accuracy. An open-ended script was developed before the focus groups and the responses of the group guided the discussion (**Box 1**).

## Data analysis

Preliminary themes were open coded with descriptive terms by the group facilitator (K.G.) at the end of each focus group. Data analysis was an iterative process as themes from the preceding groups were reviewed and member checked at subsequent focus groups, allowing new co-researchers to be involved in discussion and data analysis and returning co-researchers to be involved to ensure validity. Similarities in themes within and between focus groups were assigned similar descriptors to create thematic codes. Groups of similar themes were then grouped into conceptual ideas. Transcripts were reviewed individually by 3 authors (K.G., G.H., R.E.M.). The written transcripts and conceptual ideas were then member checked individually with 5 co-researchers to ensure validity. Theme saturation was reached with 4 focus groups, where new co-researchers reiterated themes identified earlier. Through discussion, co-researchers identified 2 action project priorities and presented these to Sheway staff. The staff discussed the action items and provided feedback to the research team, thus enhancing dependability of the findings.

### **Box 1. Example interview script from the first focus group with Empowering Mothers (October 24, 2013)**

After a welcome, introductions, a description of the study design, and ensuring consent was obtained, the following questions were used to guide the discussion:

- When you think of health care you received before, during, and after pregnancy, what are some good things that you or others have experienced?
- What are some not so good things you or others experienced before, during, and after pregnancy?
- What is one thing that could be done to make Sheway services better?
- What could a group like this one do to bring about a change for the better?
- How could Sheway do a better job of listening to clients and making changes?
- How do we measure the success of our efforts as a group?
- What could be done to help clients feel heard and respected?
- What are the next steps we should take?

## — Findings —

Four weekly focus groups were conducted at Sheway from January to February 2014, with 11 to 18 women participating in each group and a total of 21 unique participants (Table 1).

The co-researchers involved in this project were women accessing Sheway services including prenatal, postpartum, and addiction care. Each co-researcher had a different experience, but the commonality was that, as a group, women accessing Sheway services disproportionately experience trauma, poverty, violence, and marginalization in pregnancy. The experience and expertise of this group was sought to direct changes in service delivery at Sheway and beyond in Vancouver. Four main themes and 2 action projects emerged from the discussion.

### Theme 1: Sheway as family

Women described many positive aspects of Sheway and described it as a positive, welcoming, genuine, nonjudgmental place where women feel safe: “When I first came to Sheway, I had no idea what to expect and ... it was such a welcoming environment that I ended up staying.” The relationships developed at Sheway between clients and with staff were seen as a great strength of the program. Women described feeling they were part of a family, feeling safe, and feeling unconditionally accepted despite their past or present situation. Women put emphasis on the loving bonds that develop at Sheway and the common thread that develops among them despite different backgrounds. As one co-researcher put it, “They are the family you didn’t have when you were fucked up on dope. We are emotional women as it is, right, so we become attached to this place.”

Women described gaining stability in their lives through the support received at Sheway: “You go from

ACTIVITY	WOMEN
Focus group 1, January 28, 2014	1
Focus group 2, February 4, 2014	2
Focus group 3, February 11, 2014	8
Focus group 4, February 18, 2014	6
Presentation at a Sheway staff meeting, February 26, 2014	5
Reviewing the final data, May 16, 2014	6
Presentation to St Paul’s Hospital Family Medicine Program, June 5, 2014	3
Presentation at the University of British Columbia Department of Family Practice Resident Research Day, June 20, 2014	2
	1

living a really crazy lifestyle to coming to this place and this place helps you change your whole life.”

### Theme 2: Mothering and recovery as a journey

The need for support and connection with other moms and services does not end in the early postpartum period. Resources are currently focused on supporting healthy pregnancy and early postpartum care. Now that more women are stabilized in pregnancy and parenting, there is a need for ongoing support for families. Women expressed an interest in taking control of their futures but identify barriers in moving from accessing all services through Sheway to suddenly needing to access them independently in the community. Currently Sheway is funded for women up to 18 months postpartum.

When you hear ... you are no longer a client here, it’s like someone saying that they are not your friend anymore. You feel like a foster kid when you turn 19 years old and then you can’t ask your group home or foster parents and can’t go there for help anymore.

Co-researchers recognized that meeting other women in the program gave them a vision for where they could be. One woman explained “how much it means to come here and see other women who have done it. I have a vision of what is possible. This is what I have to do. I love that.”

Co-researchers who had been involved with Sheway for longer described wanting to give back to the program by supporting newer clients: “Some of us who are more ready have more responsibility to the program.”

The need for support for women and mothers at Sheway goes beyond dealing with substance use. They expressed needing continued support over time: “Just because I am not using now doesn’t mean I am ready to mentally handle everything.”

Co-researchers explained some of the many barriers to working on recovery while parenting. For example, one woman related a negative experience trying to attend a support meeting: “I brought my daughter to [a Narcotics Anonymous] meeting and I was asked ... to leave because my daughter was being disruptive. I was like ... I need to be here or I am going to fuck up. But I was told I had to go. I was really hurt.”

The mothers also challenged the view that addicts are not good parents and made the distinction that the roles of substance user and good mother overlap. They expressed that they did not want to live with one label forever: “People in regular society don’t think you can be a good mother and still have a problem ... all the ladies in this room right now I know are great mothers.”

### Theme 3: Challenges in transition

Without Sheway services, women expressed uncertainty about their future and feeling lonely and isolated.

Continued support from Sheway was described as something that would be a great resource. One co-researcher thought it would be helpful to have “Someone that can tell you what they are doing after Sheway. There are lots of resources out there.”

Co-researchers believed that if a strategy to better transition women from Sheway was not developed, the same women would end up back in the program, which would increase staff burden further: “What do you do when your file closes at Sheway? Have another baby.”

Women identified suggestions for future programming including guidance and resources on parenting, child care resources, budgeting, food resources, finding education, and relationships. As one woman described, “They prepare us for when the baby will be born but the reality is we have to raise these kids for the rest of their lives.”

A proposed solution was a transition or leadership group where women who were coming to the end of their time at Sheway could meet with women who were “graduates” of Sheway. This group would remain open to them whether they were a formal Sheway client or not: “[What] if there was some kind of continuation for us moms who are done? This is where I feel welcome.”

#### Theme 4: Considerations for family doctors

The co-researchers identified a shortage of physicians in their communities and, in particular, physicians with experience or training in offering sensitive care in relation to substance use: “They need more [doctors] down here. You need one that won’t judge you right away because you’re getting a methadone prescription.”

Training for physicians was identified as a potential mediator for negative attitudes encountered by women: “Maybe it would help [doctors] to be nonjudgmental if they could do more training. Why are the doctors here different? .... They are listening. Even though I am not a doctor, they are listening.”

Some women described experiences of maltreatment based on their history of substance use or addiction. They described not receiving the care they expected and interpreted that this was related to their substance use and health care providers’ attitudes toward substance users. One woman described her experience:

I ended up [in emergency] after I had my daughter .... As soon as they knew I had been there before and it was for an overdose, they treated me like shit. I woke up in their hospital on a cot and no one would even talk to me. They basically just gave me a bus ticket and said it’s time to go .... No one talked to me, no one [asked] what was wrong with me.

Positive experiences with health care providers were not necessarily related to providers’ training level or specialization. Having someone care and be present made a substantial positive impression: “I had an intern

come down with me ... for my [cesarean] section. She came down to the [operating room]; she held my hand. She said everything would be OK.”

#### Action projects

The co-researchers generated many ideas of ways that their care could be improved with little added funding (**Box 2**). As the focus of the project was empowerment, the outcome of the project was oriented to what type of action the group could take to improve the care of women with few added resources. Through discussion at the focus groups, the group reached consensus that the mentorship and the transition projects were priorities. The initial intake into Sheway was described as challenging, as women were unsure about what services were available and how to access services. The women expressed that the development of relationships with peers and staff was one of the program’s greatest strengths (themes 1 and 2) and a way to facilitate these relationships was seen as an achievable goal. A proposed solution was a peer-to-peer mentorship program.

Transitioning away from the program was identified as another challenge, as previously described (theme 3). The solution presented by the co-researchers was formation of a group where women could meet and talk about any issues related to transition.

Women also expressed the need for physicians including family doctors to be more aware of issues related to substance use and pregnancy and parenting (theme 4). Many in the group were eager to share their experience and create dialogue to this end and were involved in presentations to the St Paul’s Hospital Family Medicine Program (June 5, 2014), at the University of British Columbia Department of Family Practice Resident Research Day (June 20, 2014), and during BC Women’s Hospital Family Medicine Department rounds (January 15, 2016).

## — Discussion —

Women described Sheway as family. Some women described Sheway as the family they never had. The importance of nonjudgmental attitudes was a theme that arose in a previous study of Aboriginal women in the DTES when accessing services.<sup>25</sup>

The theme of mothering as a journey expressed the growth and changes that occur over time. The women expressed wanting a program that could shift with their changing needs. A key dissonance was the disconnect between supports for mothering and supports for outpatient addiction recovery. Women highlighted the stigma in society around parenting, poverty, and substance use. Working through recovery is part of the journey toward improved parenting in contrast to substance use as evidence of inadequate parenting. Women in the DTES have correctly expressed concern that disclosing their substance use puts them at risk of losing custody of their

## Box 2. Ideas generated by the focus groups to improve Sheway

### Community resources and support

- Community package with resources (eg, list of community centres, neighbourhood housing, food banks)
- Buddy system where women could go together to new community programs
- Continuation program for moms with children older than 18 mo
- Ways to share community resources and programs with each other
- Trips and outings for older children and their families; outings arranged for swimming
- Parenting skills group

### Food

- More milk, fruit, and vegetables
- Sheway community garden
- Community kitchens

### Housing

- Housing lists and support in finding housing
- Second-stage Sheway program extended to another location

### Fundraising

- Bake sale and bannock fundraiser
- Increased funding for Sheway
- Advertising Sheway to the public to gain more support
- Commercial for Sheway to get donations
- Promote Sheway
- Kids carnival at a local park
- Letter writing to corporations for donations
- Making dream catchers and beading as a fundraiser
- Sheway clothing line with maternity and baby clothing (eg, hoodies)

### Employment and income

- Small jobs helping Sheway to make extra money
- Session on budgeting
- Session on job searching
- Communal savings account where women could put in a small amount of money and bulk purchase milk, eggs, and produce
- Support to pursue education, employment, and volunteering opportunities in the community

### Recovery support

- Support for addiction management and recovery support
- Recovery support for moms specifically (eg, child-friendly meetings)
- Healing circle

### Logistical support

- Community Sheway Facebook page so women can stay connected
- Print resources with information about the Sheway program
- Go through the Sheway website together
- Calendar at Sheway drop-in with all the community activities
- Feedback box for anonymous comments

### Medical support

- Help with finding preschools, immunizations, and well-child care
- List of doctors that are interested in taking Sheway clients

Data from Saraf et al.<sup>26</sup>

children and cite this as a barrier to accessing addiction treatment.<sup>25</sup> Many women desire access to treatment to facilitate healthy pregnancies and parenting, but unfortunately there is a lack of women-centred, trauma-informed addiction treatment centres where mothers can stay with their families.<sup>25-28</sup> In a study of a similar program in Australia, women expressed wanting to be treated like “normal” expectant women rather than as “high-risk” pregnancies that needed continuous assessment and warning about risk.<sup>2</sup> This “normalization” creates a safer environment for women to address their needs and goals for pregnancy, parenting, and recovery.

Many barriers exist as women face the end of their period at Sheway and these were expressed as challenges in transition. Often women feel a sense of grief when faced with losing connections and challenged to find new supports. As women who have experienced disproportional loss and family disruption in their own lives, it seems that this systemic issue is contributing to further harm. The concerns around transition have been echoed in past studies in the DTES and at Sheway, in which participants highlighted that women need “the most help, more support” as their children grow.<sup>17,18,25</sup> When Sheway started in 1993, almost all babies born in the program were apprehended by child protection.<sup>25</sup> Just 5 years later, child protection was no longer a serious issue for most new mothers at Sheway.<sup>25</sup> This

success has created a need for transition programming and funding to support families staying together.

The final theme was considerations for family physicians, which reflects on the experiences women had with physicians and health care providers outside of Sheway. Disrespectful treatment likely stems from underlying and unrecognized values and assumptions surrounding the nature of drug and alcohol use, poverty, and pregnancy. Women challenged physicians to increase their knowledge in this area. Health care providers are encouraged to explore their beliefs around these topics and challenge their perceptions and assumptions about female substance users. Women with substance use history, and especially pregnant women, are equally deserving of high-quality patient-centred care and they disproportionately experience a great deal of psychological trauma throughout their lives.<sup>14</sup> Care providers are encouraged to explore their own beliefs around substance use and pregnancy and how this affects their work with women.<sup>29</sup>

The co-researchers had numerous ideas to improve Sheway (Box 2). Two action projects were prioritized by the co-researchers as identifiable and achievable. Representatives presented these to Sheway staff. The action phase of the project is currently ongoing and staff are assisting with the transition group project. The action items correlated with earlier study findings at

Sheway and translated the desire for a mentorship program into an actionable goal.<sup>17</sup>

## Limitations and future directions

The main limitation of this project was that of the limited time frame. Ideally this process of data collection, analysis, and action planning could be ongoing over a longer time period so as to include more women and further develop the action plans.

Future research could involve evaluating the effect of the mentorship programming on the engagement of women in care and the quality of care they receive. A framework to understand how to support Sheway women in their transition out of the program and reduce retraumatizing experiences and build resilience could also be explored.

## Conclusion

This project aimed to work with women at Sheway to conduct research within a participatory action framework. The co-researchers highlighted similar challenges reported during past projects, including the feeling of isolation and fears of leaving Sheway and transitioning to the community.<sup>18,30,31</sup> Action items identified included a transition support group and peer-to-peer mentorship, and these were endorsed by Sheway staff. This research highlights the continued need for welcoming, safe, and supportive programming for women with substance use in pregnancy. The importance of relationships for women with a history of substance use as they transition to parenting was highlighted. This work can inform health care providers in other regions to create safe, respectful relationships and integrate pregnancy, addiction, parenting, and recovery services in an accessible and trauma-informed way.

**Dr Gartner** is Assistant Professor in the Department of Family Medicine at the University of Saskatchewan in Saskatoon. **Ms Elliott** and **Ms Smith** are co-researchers with Empowering Mothers in Vancouver, BC. **Dr Pearson** is Assistant Professor in the Department of Family Practice at the University of British Columbia and a counselor with the Centre for Practitioner Renewal in Vancouver. **Dr Hunt** is Assistant Head, Quality in the Department of Family Practice at the University of British Columbia and Physician Lead for Sheway in Vancouver. **Dr Martin** is Clinical Professor in the School of Population and Public Health at the University of British Columbia.

### Acknowledgment

The authors wish to acknowledge that this research was conducted on unceded Coast Salish Territory of the Musqueam, Squamish, and Tsleil-Waututh First Nations. The legacy of colonialism, residential school policy, and systemic racism continues to affect the community participants in this work. We thank the Empowering Mothers focus group participants without whom this work would not be possible. We thank Sheway staff for the excellent care they provide and for assisting with recruitment and sign-up, allowing use of their space, and supporting the project. We also wish to thank **Georgia Hunt**, **Heather McEwen**, and **Erin Knight** for volunteering for child care during the focus groups. This project received funding from the Sue Harris Family Practice Grant from the Women’s Health Research Institute and the St Paul’s Hospital Family Medicine Program at the University of British Columbia. We also thank **Anita Hotty**, who participated in knowledge translation and presentations of this project to physicians and residents in Vancouver, BC. The views and opinions expressed are those of the authors and focus group members and do not necessarily reflect the views of Sheway or Vancouver Coastal Health.

### Contributors

**Dr Gartner** designed the study with the other authors, facilitated focus groups, transcribed the data, analyzed the transcripts, and prepared the manuscript. **Ms Elliott** and **Ms Smith** participated in the focus groups, assisted in member checking data and reviewing themes, and assisted in knowledge translation and presentations. **Dr Pearson** independently reviewed the transcripts, gave input on data analysis, and edited the manuscript. **Dr Hunt** identified the need for the study, assisted with design, supervised child care during focus groups, and independently reviewed the transcripts. **Dr Martin** gave input on the design of the study, independently reviewed the data and themes, and edited the manuscript.

### Competing interests

None declared

### Correspondence

**Dr Kali Gartner**; e-mail [KGartner@communityclinic.ca](mailto:KGartner@communityclinic.ca)

### References

- Ordean A, Kahan M, Graves L, Abrahams R, Boyajian T. Integrated care for pregnant women on methadone maintenance treatment. Canadian primary care cohort study. *Can Fam Physician* 2013;59:e462-9. Available from: [www.cfp.ca/content/cfp/59/10/e462.full.pdf](http://www.cfp.ca/content/cfp/59/10/e462.full.pdf). Accessed 2018 May 31.
- Morris M, Seibold C, Webber R. Drugs and having babies: an exploration of how a specialist clinic meets the needs of chemically dependent pregnant women. *Midwifery* 2012;28(2):163-72. Epub 2011 Jun 11.
- Benoit C, Carroll D, Chaudhry M. In search of a healing place: Aboriginal women in Vancouver’s Downtown Eastside. *Soc Sci Med* 2003;56(4):821-33.
- Wong S, Ordean A, Kahan M. Substance use in pregnancy. *J Obstet Gynaecol Can* 2011;33(4):367-84.
- Hawthorne JL, Maier RC. Drug abuse in an obstetric population of a midsized city. *South Med J* 1993;86(12):1334-8.
- Corraro JE, Williams C, Campbell WS 3rd, Amrheer E, LoPiano L, Kalachik D. Linking substance-abusing pregnant women to drug treatment services: a pilot program. *J Obstet Gynecol Neonatal Nurs* 2000;29(4):369-76.
- Cartwright PS, Schorge JO, McLaughlin FJ. Epidemiologic characteristics of drug use during pregnancy: experience in a Nashville hospital. *South Med J* 1991;84(7):867-70.
- Kelly L, Guilfoyle J, Dooley J, Antone I, Gerber-Finn L, Dooley R, et al. Incidence of narcotic abuse during pregnancy in northwestern Ontario. Three-year prospective cohort study. *Can Fam Physician* 2014;60:e493-8. Available from: [www.cfp.ca/content/cfp/60/10/e493.full.pdf](http://www.cfp.ca/content/cfp/60/10/e493.full.pdf). Accessed 2018 May 31.
- Velez ML, Jansson LM, Montoya ID, Schweitzer W, Golden A, Svikis D. Parenting knowledge among substance abusing women in treatment. *J Subst Abuse Treat* 2004;27(3):215-22.
- Benoit C, Carroll D. *Marginalized voices from the Downtown Eastside: Aboriginal women speak about their health experiences*. Toronto, ON: York University; 2001.
- Howell EM, Heiser N, Harrington M. A review of recent findings on substance abuse treatment for pregnant women. *J Subst Abuse Treat* 1999;16(3):195-219.
- Curet LB, Hsi AC. Drug abuse during pregnancy. *Clin Obstet Gynecol* 2002;45(1):73-88.
- Lee HS, Zerai A. “Everyone deserves services no matter what”: defining success in harm-reduction-based substance user treatment. *Subst Use Misuse* 2010;45(14):2411-27. Epub 2010 Apr 16.
- Torchalla I, Linden IA, Strehlau V, Neilson EK, Krausz M. “Like a lot happened with my whole childhood”: violence, trauma, and addiction in pregnant and postpartum women from Vancouver’s Downtown Eastside. *Harm Reduct J* 2015;11:34. Erratum in: *Harm Reduct J* 2017;14:65.
- Marshall SK, Charles G, Hare J, Ponzetti JJ Jr, Stokl M. Sheway’s services for substance using pregnant and parenting women: evaluating the outcomes for infants. *Can J Commun Men Health* 2005;24(1):19-34.
- Sword W, Niccols A, Fan A. “New choices” for women with addictions: perceptions of program participants. *BMC Public Health* 2004;4:10. Epub 2004 Apr 15.
- Poole N. *Evaluation report of the Sheway project for high-risk pregnant and parenting women*. Vancouver, BC: British Columbia Centre for Excellence in Women’s Health; 2000.
- Burglehaus M, Stokl M. Sheway: supporting choices and self-determination. *J Aborig Health* 2005;2(1):54-61.
- Linden IA, Mar MY, Werker GR, Jang K, Krausz M. Research on a vulnerable neighborhood—the Vancouver Downtown Eastside from 2001 to 2011. *J Urban Health* 2013;90(3):559-73.
- McCall J, Lauridsen-Hoegh P. Trauma and cultural safety: providing quality care to HIV-infected women of aboriginal descent. *J Assoc Nurses AIDS Care* 2014;25(1 Suppl):S70-8. Epub 2013 Sep 4.
- Creamer S, McMurtrie C. Special needs of pregnant and parenting women in recovery: a move toward a more woman-centered approach. *Womens Health Issues* 1998;8(4):239-45.
- Macroy F, Boyd SC. Developing primary and secondary services for drug and alcohol dependent mothers. *Semin Fetal Neonatal Med* 2007;12(2):119-26. Epub 2007 Mar 6.
- Baum F, MacDougall C, Smith D. Participatory action research. *J Epidemiol Community Health* 2006;60(10):854-7.
- Tracy SJ. *Qualitative research methods: collecting evidence, crafting analysis, communicating impact*. Chichester, UK: Wiley-Blackwell; 2013.
- Gilbert L, el-Bassel N, Schilling RF, Friedman E. Childhood abuse as a risk for partner abuse among women in methadone maintenance. *Am J Drug Alcohol Abuse* 1997;23(4):581-95.
- Finkelstein N. Treatment programming for alcohol and drug-dependent pregnant women. *Int J Addict* 1993;28(13):1275-309.
- Scott-Lennox J, Rose R, Bohlig A, Lennox R. The impact of women’s family status on completion of substance abuse treatment. *J Behav Health Serv Res* 2000;27(4):366-79.
- Brown JD, Vartivarian S, Alderks CE. Child care in outpatient substance abuse treatment facilities for women: findings from the 2008 national survey of substance abuse treatment services. *J Behav Health Serv Res* 2011;38(4):478-87.
- Benoit C, Stengel C, Marcellus L, Hallgrimsdottir H, Anderson J, MacKinnon K, et al. Providers’ constructions of pregnant and early parenting women who use substances. *Social Health Illn* 2014;36(2):252-63.
- Krausz M. *Addiction in maternity: mixed methods study on substance use during maternity, access to services and perceptions of addiction in maternity*. Vancouver, BC: Centre for Health Evaluation and Outcome Sciences, University of British Columbia; 2010.
- Whynot EM. Women who use injection drugs: the social context of risk. *CMAJ* 1998;159(4):355-8.

This article has been peer reviewed.

Cet article a fait l’objet d’une révision par des pairs.

*Can Fam Physician* 2018;64:e309-16