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A qualitative cancer screening study with childhood sexual abuse survivors: experiences, perspectives and compassionate care

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ABSTRACT

Objective: The childhood sexual abuse (CSA) survivor population is substantial and survivors have been identified as part of the population who were under-screened or never-screened for breast, cervical and colon cancer. Our objective was to learn CSA survivor perspectives on, and experiences with, breast, cervical and colon cancer screening with the intention of generating recommendations to help healthcare providers improve cancer screening participation.

Design: A pragmatic constructivist qualitative study involving individual, semistructured, in-depth interviews was conducted in January 2014. Thematic analysis was used to describe CSA survivor perspectives on cancer screening and identify potential facilitators for screening.

Participants: A diverse purposive sample of adult female CSA survivors was recruited. The inclusion criteria were: being a CSA survivor, being in a stable living situation, where stable meant able to meet one's financial needs independently, able to maintain supportive relationships, having participated in therapy to recover from past abuse, and living in a safe environment. 12 survivors were interviewed whose ages ranged from the early 40s to mid-70s. Descriptive saturation was reached after 10 interviews.

Setting: Interviews were conducted over the phone or Internet. CSA survivors were primarily from urban and rural Ontario, but some resided elsewhere in Canada and the USA.

Results: The core concept that emerged was that compassionate care at every level of the healthcare experience could improve cancer screening participation. Main themes included: desire for holistic care; unique needs of patients with dissociative identity disorder; the patient-healthcare provider relationship; appointment interactions; the cancer screening environment; and provider assumptions about patients.

Conclusions: Compassionate care can be delivered by: building a relationship; practising respect; focusing attention on the patient; not rushing the appointment; keeping the environment positive and comfortable; maintaining patient dignity; sharing control whenever possible; explaining procedures; and using laughter to reduce power imbalance through shared humanity.

Strengths and limitations of this study

- A major strength of our study was taking a community-based research approach and having a childhood sexual abuse (CSA) survivor actively participate in all aspects of the research including formation of the research question, development of research methods, data collection, data analysis, interpretation and dissemination of study findings.
- Another strength was the inclusion of perspectives from participants with dissociative identity disorder.
- Phone interviews were not voice recorded but rather transcribed in real time to support CSA survivors who may have a history of being video and/or audio recorded for exploitation purposes.
- We did not interview female CSA survivors aged below 40 years or male CSA survivors, although we hypothesise that the recommendation of compassionate care will resonate with both these groups.

INTRODUCTION

Adverse childhood experiences, especially around sexual abuse, have been associated with significantly increased risk for a wide range of physical and mental health problems,[1] including post-traumatic stress disorder and dissociation,[2–8] as well as significantly increased odds of adult cancer diagnosis.[9–11] The reasons for this latter association are complex and not fully understood;[12] however, some possibilities include that childhood sexual abuse (CSA) survivors may be: exposed to the human papilloma virus (HPV) responsible for cervical cancer[13] earlier in life and more often, less likely to access preventative healthcare, or less likely to participate in routine cancer screening programmes that can change the natural history of disease.[14–18] CSA survivors have been identified as a population with low rates of cervical,[15–22] breast[23 24] and colon[25] cancer

screening participation.[14] This is understandable since these screening tests involve squeezing and penetrating the body's most intimate sexual sites—those same sites that were physically traumatised for CSA survivors.

It is very challenging to accurately estimate the CSA population given the variability in definitions of CSA and difficulties in measuring CSA.[26 27] Currently, the best estimates of CSA are that between 12% and 18% of girls and between 5% and 8% of boys aged 2–17 years have experienced higher-impact CSA.[27] The evidence also indicates that CSA cases are significantly unreported, suggesting that the CSA survivor population is substantial.[28] Add individuals who have survived other forms of sexual abuse, such as forced sex or sexual violence as youth or adults, and the sexual abuse survivor population grows rapidly.

A few studies have identified barriers to cervical cancer screening for CSA survivors, including not wanting to be touched in the pelvic area and dissociating areas of the body.[14 20] Fewer studies have identified facilitators to cervical cancer screening, such as improving communication, safety, trust and sharing control.[21] There is a dearth of studies identifying barriers and facilitators to breast[23] or colon[25] cancer screening. Our objective was to learn CSA survivor perspectives on, and experiences with, breast, cervical and colon cancer screening with the intention of generating recommendations to help healthcare providers improve cancer screening participation.

METHODS

We approached this research from a pragmatic constructivist perspective[29] and used a community-based participatory research (CBPR) approach[30–33] to conduct cancer screening research with CSA survivors. CSA survivors are a hidden, hard-to-reach population because of shame, guilt and stigma and many have not disclosed their prior abuse openly. CSA survivors are also a vulnerable population because of their history of abuse, trauma and exploitation. We chose to take a CBPR approach and worked closely with a community 'gate-keeper' to: increase research safety and relevance; maintain rigour in the development of sensitive and supportive interview methods; increase access, uptake, recruitment and participation in interviews; strengthen the accuracy, rigour and reliability of our data analysis and interpretation; aid knowledge translation; and maximise participant support and community benefit.[33–36]

CSA survivors who have worked with therapists or other healers to address their past abuse have reduced vulnerability because they have healed enough and are strong enough to be able to say no and so provide free and informed consent. This vulnerability is further reduced when CSA survivors interact with other members of the CSA survivor community, where relationship, trust and rapport are more quickly established because of shared experience and mutual understanding.

Our CSA survivor community partner (LN) is an internationally recognised author and advocate who writes, speaks and educates about sexual abuse. She has extensive experience researching sexual abuse and interviewing CSA survivors, including CSA survivors with dissociative identity disorder (DID)—a "complex and valid disorder that is not uncommon"[37] and is often associated with CSA.[37 38]

Our community partner was the point person for recruitment and interviewed all participants. A first pass of CSA survivors was contacted by our community partner through her pre-existing network as the moderator of an online CSA support group and internationally recognised CSA author and advocate. Survivors were contacted by email, phone and chat room post to tell them about the project. We maximised the breadth and diversity of participants by purposively sampling CSA survivors with varying cancer screening habits (never-screened, under-screened, or regularly screened), socioeconomic status and education levels, as well as residing in urban or rural Ontario, or elsewhere in Canada or the USA. We extended our sampling reach by asking those who participated if there was anyone else with whom we should talk in a modified snowball sampling approach. Those interested in participating contacted our community partner directly to schedule an interview.

The inclusion criteria were: being part of the CSA survivor community and being in a stable situation, where stable meant able to meet one's financial needs independently, able to maintain supportive relationships, having had therapy/psychotherapy to recover from past abuse, and currently living in a safe environment. We focused on women aged 50 years and older because the standard screening age requirements for breast and colon cancer are 50 years old and above. However, we also interviewed CSA survivors in their 40s to capture the perspectives of women with a long history of cervical cancer screening eligibility and approaching the age of eligibility for breast and colon cancer screening. Participants needed to have access to the Internet or a phone for the interview.

Individual, semistructured, in-depth interviews (see online supplementary appendix I) were conducted with CSA survivors in January 2014. Participants were guided to be in a comfortable, secure location of their choosing for their interview. All interviews were anonymous. Only the community interviewer knew the identity of participants. All interviews were initiated with a review of the purpose of the research and sustained in a natural conversational style.[39] Participants were asked to talk about their experience in seeking medical care in general and then specifically about breast, cervical and colon cancer screening as relevant to them. They were also asked what healthcare providers can do to make it easier to get screened and if there was anything else they wanted to say or thought we should know. Outside researchers reviewed interview questions, probes and the flow before the interview guide was finalised.

Interviews took 45 min to a little over 1 h to complete. Participants were given the option of having their interview over the phone or via an online chat. One participant requested to complete the interview by email. Our community interviewer helped develop the research question and interview guide, and so was trained in the spirit and intention of the research[40] so that she could ensure consistency of the information collected across all interviews, regardless of the manifestation of conversation or interview modality. Descriptive saturation was reached once our community interviewer noticed no new information arising during interviews. Participants were compensated for their time and knowledge with a monetary honorarium.

For many CSA survivors, sexual abuse included video and/or audio recording for exploitation purposes, resulting in many CSA survivors being triggered by voice or image recording. Therefore, phone interviews were not voice recorded. Instead, phone conversations were transcribed directly into a computer in real time and supplemented with detailed notes after the interview. Every effort was made to capture the conversation verbatim. Online chat interviews were already transcribed verbatim through the written record. All transcripts were anonymous. Field notes were taken to record both verbal and non-verbal insights and salient points learnt during interviews.

Throughout the interview, the community interviewer: empowered participants by expressing the value of their participation; used personal sharing (as helpful) to build rapport, safety and trust; provided support and validation to help participants through emotions that arose during the interview; paid attention throughout the interview to how the participant was feeling; and checked in at the end of each interview to make sure that the participant was emotionally stable and supported. The interview focused on experiences with the medical system and cancer screening; however, the conversation had the potential to touch on past memories of abuse, which could have brought up old feelings, which may or may not be distressing to participants who had benefited from therapy. If a participant had expressed sadness or sorrow, they would have been asked how they wanted to proceed (eg, sit quietly while they work through the emotion, take a break, continue or finish up early) and that request would have been honoured. One participant felt sad, but was okay to continue and felt positive about completing the interview. If a participant had felt that they needed additional support, we would have covered the cost of one session with their therapist. None of the participants requested therapy session support.

Our community interviewer had a follow-up conversation with each participant 1 week after their interview to see if the interviewee had additional comments and was comfortable with the interview process and what came out during the conversation. Preliminary data analysis results were also reviewed at this time (member checking). This follow-up conversation contributed to the rigour of our data collection and analysis. It also provided an opportunity to check the emotional state of the participant and help resolve any unresolved issues raised by the research process. No unresolved issues remained.

Thematic analysis[41 42] was used to identify and describe CSA survivor perspectives on cancer screening and potential facilitators for screening. We increased rigour, validity and the fullness of the analysis and interpretation by having two separate researchers with different perspectives conduct the analysis—one, a CSA survivor, and one with no history of sexual abuse. Transcripts were read and coded simultaneously. Codes were grouped around similar ideas into categories. Codes and categories were constantly compared across cases for corroboration and consistency. Categories were organised into themes and subthemes describing aspects of the data using an inductive approach. The two researchers identified themes, then came together to share and discuss results so that one perspective did not dominate the interpretation of results and to ensure that saturation had been reached. Themes were framed in the context of recommendations for improving cancer screening participation. Discrepancies were discussed until reconciled and interpretation and recommendations were agreed on. Descriptive saturation was confirmed during thematic analysis when no new codes, categories or themes emerged from the data. Field notes were used to aid interpretation of themes. Illustrative quotes are used to support themes, interpretations and recommendations.

We included the consolidated criteria for reporting qualitative studies (COREQ) 32-item checklist (see online supplementary appendix II).

RESULTS

Initially, 13 CSA survivors were informed about the study. Twelve of them agreed to participate in an interview after seed and snowball sampling. All 12 were interviewed in January 2014. None dropped out. All agreed to follow up. Descriptive saturation was reached after 10 interviews; however, two additional participants were interviewed to honour snowball referral and confirm saturation.

All participants were female. Their ages ranged from the early 40s to mid-70s: 3 were in their 40s, 6 in their 50s, 2 in their 60s and 1 in her 70s. Education ranged from limited formal education to postgraduate degrees. CSA survivors lived in rural (n=4), small town (n=5) and urban (n=3) communities in Canada (n=9) and the USA (n=3). Nine CSA survivors were mothers and two were First Nations. Three participants disclosed having DID and had more than one personality participate in the interview, though it is likely that more than three participants were DID since DID is highly stigmatised and even debated in the psychiatric world,[37] making it a condition most multiples will not readily disclose.

All participants had been screened at least once for at least one type of breast, cervical or colon cancer in the past. However, some participants had never been screened for all three cancers, despite being eligible. Most participants were under-screened for all three cancers. Few were up to date for all eligible cancer screening tests.

Survivors wanted to be healthy and recognised the importance of personal agency in staying healthy. Survivors identified several ways healthcare providers could help support patient efforts to "…be responsible for [our] own health" (Int 1).

The core concept that emerged was that CSA survivor participation in cancer screening was supported most by compassionate care. Compassionate care means providers relating to CSA survivors, or any patient, on a human level, by understanding, empathising and mitigating potential sources of suffering. It is also the overarching term we use to summarise the themes and subthemes from our analysis, including: the desire for holistic care; the unique needs of CSA survivors with DID; the patient—healthcare provider relationship; appointment interactions; the cancer screening environment; and provider assumptions about patients. Each theme is described below in detail.

Desire for holistic care

A common theme that CSA survivors used to exemplify the concept of compassionate care was holistic care, which balances physical, mental, emotional and spiritual health (table 1). Some CSA survivors perceived that they would be able to take better care of themselves if healthcare providers were more holistic in their approach, attending to the emotional or psychological supports needed to overcome the anxiety of cancer screening. They also suggested that helping CSA survivors recognise and value the mind-body connection might help them adopt healthy behaviours. By extension, strengthening the mind-body connection and providing emotional and psychological support may have the added benefit of preventing CSA survivors from dissociating during screening procedures.

The unique needs of CSA survivors with DID

We found that DID could affect cancer screening both in terms of accessing and participating in screening programmes. One participant shared: "We have to take responsibility for our health. I can tell the younger ones too. Some things are not comfortable but it is for making us healthy." (Int 6). This statement provides a glimpse into the complexity of decision-making for someone with DID. Balancing the potentially competing thoughts, opinions, concerns and anxieties of multiple personalities can impact the decision to access cancer screening.

Conflict around the 'legitimacy' of DID in the psychiatric world[37] is not helping people with multiple personalities (multiples) access healthcare services or get the care they need. The debate can impact the way some doctors interact with patients with DID and thus undermine the experience and trust. As one participant with DID described: "I think mostly my psychiatrist, they don't really take it seriously, the mental illness. I would like to be treated like a person and when I tell them I was diseased with something to take them seriously and when I need care, give me the care that I need." (Int 7).

Furthermore, healthcare providers should be aware that a patient with DID may either show up to an appointment in a younger state or have a younger personality come forward during an appointment:

> "For me, I'm fortunate in having a wonderful [doctor] who knows my [disorder] and in fact on one occasion going back quite a number of years, I made an appointment in a young state. He treated me as usual, his tone changed in a gentle way." (Int 6)

CSA survivors without DID may also dissociate during a screening procedure (table 1). Doctor awareness of the mental and emotional state of the patient, changes in state, and providing compassionate care may facilitate present and future cancer screening participation.

Relationship with healthcare providers

The relationship CSA survivors have with their doctor, nurse practitioner, laboratory technician and support staff has an effect on how they feel about healthcare and whether they seek cancer screening (table 1). Positive relationships and experiences with healthcare providers and the healthcare system had lasting effects for many CSA survivors, and they would use these positive relationships and experiences to counterbalance or even neutralise more negative medical experiences.

Appointment interactions

The quality of the interaction with a healthcare provider during appointments was identified as a significant facilitator (or barrier) to cancer screening for CSA survivors. Recommended actions and interaction characteristics centred around the provider–survivor relationship and focused on the provider being mentally present and respectful; communication styles; being mindful of body language; maintaining the Survivor's dignity; sharing control; and being 'human'.

Being mentally present and respectful

Healthcare providers may have the deepest respect for their patients, but unless they communicate it, the patient is not likely to know it, especially those who have been abused. Patients felt respected when they had their provider's attention and could tell when their healthcare provider's mind and attention were elsewhere (table 1). Participants suggested that healthcare providers demonstrate being present and respectful by listening, being reassuring, being aware and not rushing the patient or appointment, even when the appointment was brief.

Table 1 Themes from interviews with childhood sexual abuse survivors about cancer screening, January 2014

Theme	Supporting quotation(s)
Holistic care	"Doctors aren't that great at attending to emotional or psychosocial issues they should know impact tremendously on health. Stress levels. The whole mind-body connection. Being more attentive to that …Help people make the mind-body connection. And doctors should become more aware of what is out there, the kind of help, not just [western] medicine—meditation, mindfulness, energy work that would be helpful to patients rather than just medicine." (Int 12) "I used to experience terror before seeing doctors or nurses. Now it is typically mild anxiety but if it were for an invasive test it's more likely to be extreme anxiety…"(Int 11)
Dissociation and dissociative identity disorder	"When they put that metal thing inside myself, it brings up a lot." (Int 4) "Is there anything that makes it easer? (Interviewer) "I go inside myself and I think of positive." (Int 4) "It was positive…there was a nurse in the room and [the Doctor] explained everything he was doing…for me it would have been easier if they wouldn't have talked to me because I could just "not be there"…it's hard to dissociate when someone's talking to you" (Int 3) "I might have a constant low to medium grade anxiety for the whole day before I go. Unless I dissociate the reason I am going and then I might be almost sort of okay until right when I get there and then I realize and I'm like $%&!! I forgot I was having that done today…. There have also been times that I have spaced out completely during the test and been unable to speak or respond and then she just works as quickly as she can, and that is probably the best thing for me at that point too. Theoretically she could see if she could get me grounded before continuing but I don't know that it would be possible at that point and I'd rather just finish the test than have to go back again. Actually I probably wouldn't be able to go back again at that point, it would be too hard." (Int 11)
Patient-provider relationship	"I am lucky to have had great doctors and nurses, and they get to know you pretty well…. I have been very reassured to see how providers do consider women in their practices." (Int 8) "During a pap test, what my doctor does that helps me the most is 1) she tells me what she is doing before she does it, and 2) she talks to me during it, about other things. Most often she asks me about my work, I think she knows that grounds me the most." (Int 11) "What I liked about it is that she understood you were nervous. She talked through step by step what she was going to do. She respects your dignity. (Int 7) "How did you know she respects your dignity? (Interviewer) "By the way she treated me, and the way she explained everything and said, 'Relax, it's going to be ok, it's going to be over in no time'. The way she spoke to me." (Int 7)
Appointment interactions	"I think nobody can go wrong if they treat patients with respect, which would be on everybody's list of recommendations. Just to be respectful, and just be aware. If someone seems to be especially anxious, just kind of, bring it out in the open….Most of the doctors that work on children, they work on their posture with their kids so they don't come across as intimidating to the kids. That kind of information would be helpful even with adults. Be aware of body language and body position. Whether it comes across as more intimidating or not." (Int 10) "If they have a sense of humor that would be nice too. But to be personable and a little light." (Int 2) "…if they kind of acknowledge that maybe using a sense of humor" (Int 9) "It would be even better if, rather than just telling me what she is about to do, if she would ask me 'Is it okay for me to do X now?' 'I am about to do Y, is that okay?' It's a subtle difference but can be important, it would keep reminding me that I have some control with this." (Int 11)
Cancer screening environment	"It doesn't take any extra time to speak to someone with a kind voice or to smile at them. Even if it did take a few minutes to help someone feel safer, it may make the test itself go more smoothly, which could save time overall." (Int 11) "What helps me most is having female providers who are kind and open with a good sense of humor. Sadly, it may be safe to assume that at least some patients will have a trauma history with anxiety around physical issues and medical visits, but a quiet and compassionate demeanor for me is a great help, as is the framing of health care as caring for oneself." (Int 8)

Continued

Table 1 Continued

Theme	Supporting quotation(s)
Provider assumptions	"I think they should have that same regard for everybody. Then they wouldn't have to worry about making exceptions or treating us differently. They would have that regard and respect for everyone…If it's good for people who've been abused, it's good for everyone. It's a win-win situation. Everybody would benefit." (Int 6) "Every doctor whether you've been abused or not should take time to listen, to ask certain questions, how they're feeling. Develop a bit more rapport… The whole tenet of compassionate care." (Int 12)

Communication styles

Several CSA survivors said their decision to participate in cancer screening was impacted by the way their healthcare provider talked with them and suggested that humour could help relieve some of the anxiety of screening (table 1). They also suggested: "…it would be very helpful if they learned something about motivational interviewing" (Int 12). Motivational interviewing[43] is a therapeutic conversational style that focuses on the autonomy of the individual, collaboration between the individual and healthcare provider, and evoking sustainable behaviour change in the individual. It was developed to help alcoholics overcome their addiction[44] and has shown promise in supporting other positive behaviour change.[45]

Being mindful of body language

Body language communicates as much as (or more than) words and so impacts provider-survivor interactions. CSA survivors recommended that healthcare providers be mindful of body language in terms of how body language can communicate both attention and intimidation (ie, make sure body language is not intimidating) to facilitate feeling comfortable with cancer screening (table 1). Aggressive or sudden movements during physical examination or procedure by healthcare providers can be equally triggering for CSA survivors. For example, one CSA survivor was startled and frightened when a phlebotomist grabbed her arm without warning. CSA survivors, like most patients, prefer not to be "treated like a piece of meat." (Int 2).

Maintaining survivor dignity

CSA survivors were not treated with dignity as children. Reminding CSA survivors that they are worthy of honour and respect by treating them with dignity is not only empowering, but also helps them get screened for cancer. Several CSA survivors recommended that simple ways to maintain patient dignity included: keeping patients covered with a blanket throughout a procedure; the provider saying what they are going to do before doing it; letting patients get dressed and 'put back together' before discussing things further because "nobody wants to sit there naked any longer than they have to!" (Int 3).

Sharing control

As children, many CSA survivors were poked and penetrated with unknown objects that they could not see and had many things done to them without their consent or knowledge of what was happening to them. Many CSA survivors said they were more likely to become comfortable with screening if they felt they understood a procedure and shared in the control of what was happening to them and their environment (table 1). Sharing control was as simple as talking to patients in plain language and asking simple questions so that they felt part of the conversation: "Just being asked these kinds of questions makes me feel more included." (Int 2).

Sharing control was about feeling they were an active and efficacious participant in the screening process. This was done by offering the CSA survivor a choice, whenever possible: "They always ask before they touch me and explain the reason for what they do, and do nothing until I say 'o.k.'" (Int 8). Demystifying the cancer screening process by explaining what is being done and what medical instruments are being used could increase CSA survivor comfort with, and participation in, cancer screening.

Being human

The most easily accessible and effective way to build rapport, mutual respect and inclusivity with CSA survivors was by establishing a commonality: "we are both human." Two of the simplest, most effective ways of relating on an equal basis described by CSA survivors were sharing personal anecdotes and laughing. As one CSA survivor described, "She is not above sharing" (Int 9). CSA survivors indicated that even a bit of humour could quickly improve healthcare interactions and transform the screening experience (table 1). Our community interviewer shared personal stories and used humour during interviews to create a calm, open and safe environment for participants and as a launch point for participants to feel comfortable sharing their stories and recommendations. We believe these were key elements in the success of the interviews.

The cancer screening environment

Cancer screening tests can be triggering for CSA survivors in ways people without this history cannot fully

predict or appreciate. As children, many CSA survivors were repeatedly abused and, after being humiliated, were left lying naked in a cold place:

> "A heater in the room. I have a feeling probably won't be. Probably not that warm. They have clothes on. I wouldn't feel cold. It's a huge trigger. How many times as a kid lying naked in a cold place. I don't want people touching me when I'm cold." (Int 12)

The choppy disconnected sentences used to communicate this recommendation lends additional paraverbal insight into how post-traumatic stress and the trauma of CSA can impact healthcare seeking and experiences in adulthood.[17 18] Keeping the physical environment comfortable and warm may help prevent triggers around being cold. Environment not only meant the physical environment though, and also included the cultural climate (table 1). Little things, like a smile or eye contact, could have a large positive impact. Female provider preference was also common among participants.

Assumptions

Some healthcare providers struggle with whether to ask patients if they have experienced sexual abuse. We found that while some survivors appreciate being asked this question and felt it gave them permission to disclose, others found it intrusive. The main difference in reaction was grounded in why the CSA survivor felt the doctor/nurse was asking the question. That is, was the question motivated by genuine concern or because it was a perfunctory item on a checklist. It was suggested that healthcare providers deliver the best care when they treat everyone like they are a sexual abuse survivor (table 1).

Other noteworthy observations

Many CSA survivors had limited knowledge and understanding of cervical cancer screening and the Pap test, including highly educated survivors. Many did not know the term 'cervix' or where the cervix is located, or the term 'speculum', what it is and what it is used for. Women with hysterectomy were unsure how much of their reproductive tract had been removed and whether they still needed cervical cancer screening. Several survivors identified exposure to radiation during mammography as a barrier to breast cancer screening.

Healthcare providers may have opportunities to educate patients during clinic visits and should not assume that patients/clients know or correctly remember sexual and reproductive health information that might help them decide to participate in screening programmes. Clinic visits present an opportunity to review how to take care of one's sexual health, including screening possibilities (sexually transmitted infections, cervical cancer, breast cancer, colon cancer) and the tests themselves.

Another observation was that the phrase 'shoved inside' came up in a number of interviews when describing the Pap test. The phrase is violent and uncaring, and speaks to the perception that some CSA survivors have of cancer screening procedures—one that reiterates the abusive experience.

Finally, structural barriers were identified by women living in isolated areas where cancer screening tests, such as mammography, may only be offered at specific times of the year:

> "I do regular cancer screening, I'm overdue. I have a stool test that I'm supposed to have done, and haven't done it yet because we have to bring it in on a Monday. Otherwise it can't get done and be valid. Because we live isolated there are extra hoops so I'm overdue on a mammogram. And I have a pap test that's supposed to be done this spring." (Int 1)

DISCUSSION

CSA survivors described compassionate care as being beneficial at every level of the healthcare experience including: when working with patients who have DID; the patient-healthcare provider relationship; appointment interactions; the cancer screening environment; and provider assumptions about patients. They suggested that compassionate care could be delivered by: providing holistic care; building a relationship; practising respect; focusing attention on the patient; not rushing the appointment; keeping the environment positive and comfortable; maintaining patient dignity; sharing control whenever possible; explaining procedures; and using laughter to reduce power imbalances through shared humanity. We further suggest that healthcare providers use these recommendations as best practice standards regardless of patient disclosure of trauma history.

These results were used to develop an informational video for the medical community on "Compassionate Care: Sexual Abuse and Cancer Screening" (available for streaming or download through YouTube, http://www.getscreened.ca, or online supplementary files). The intention was for this video to be a resource for: educational institutions (medical training programmes, nursing programmes, allied health programmes) to train new healthcare providers, healthcare facilities to train new or existing staff, continuing education credits for healthcare providers already delivering care to CSA survivors, or simply for healthcare providers searching the web to learn how to better support CSA survivor clients.

Our recommendations reinforce and add to those of other sexual abuse and cancer screening studies that have proposed focusing on "communication, safety, trust and sharing control"[20] and developing interventions that reduce distress.[17 25] Our finding that several CSA survivors appreciate when providers talked with them through procedures suggests that cancer screening participation could be improved with interventions and outreach efforts that provide psychoeducation about screening procedures, such as optional consultation

meetings prior to screening or community health information evenings targeting larger groups. This type of intervention is further supported by our findings that some women have limited knowledge or understanding of cervical cancer.

Our findings also reveal that CSA survivors with or without DID may dissociate during medical procedures as a way of coping with stress and anxiety, providing contextual evidence of the long-term impact of post-traumatic stress disorder from CSA.[2–8 37 38 46] This finding highlights the unique needs of CSA survivors, especially those with DID who may also have to balance internal competing perspectives on screening and may arrive to an appointment in a younger state. DID CSA survivors indicated that providers who adjusted their interaction style to meet the needs of their presenting identity felt supported through the screening process, which facilitated their participation through to completion. These positive experiences also helped reduce anxiety, maintained rapport and a positive patient–provider relationship, and encouraged CSA survivors to continue participating in screening programmes.

A major strength of our study was having a CSA survivor conduct the interviews and participate in the analysis. First, our community partner knew how to approach participants to ensure their safety and she was able to recognise from experience that we would need to remain flexible about how information was shared, gathered and recorded. As it turned out, it was very important to let participants decide how they would communicate and this was reinforced when one of the participants requested an alternative form of communication:

> "I think that I'm having anxiety around our Skype date, even as chat…. Would it be o.k. if we follow up via e-mail, at least around this project, for now? I'm very comfortable with that option. And I apologize if this interferes with the research in any way, because I think that the project is really worthwhile." (Int 8)

Remaining flexible ensured that all CSA survivor voices had a chance to be heard. Having our community partner participate in the analysis helped identify and prioritise themes and recommendations that may have otherwise been disregarded or taken for granted.

Our community partner has had many years of interactions with people with DID, which enabled her to interact with participants with DID in a way that obtained different points of view from those parts (identities) who presented. Her experience and sensitivity towards DID helped participants with DID, who would normally pose as a singleton with a different interviewer, be themselves and present different parts over the course of a single interview. Only one subject overtly presented different parts. Others who self-identified switched without overtly presenting, and although she changed her interview style according to the presentation, she did not comment on the change in those cases.

The interview process itself turned out to be an example of what participants recommended; that is, using humour, paying attention and sharing. A number of participants spoke about feeling very positive about the interview and their contribution. Specifically, one interviewee went to her doctor to discuss the HPV vaccine because of what she learnt during and following her interview. Another interviewee said that the experience gave her the confidence to enter into her first sexual relationship in many years, a positive one in the context of a romantic relationship.

The absence of an audio recording was a consideration of the study population and facilitated CSA survivor participation and safety; however, it is still a methodological limitation of our study. This limitation primarily affected CSA survivors who interviewed orally. Participants who participated through an online chat were recorded verbatim through the written record. The role of video and audio recording is an important consideration that should be researched more intentionally and formally given its sensitive and potentially triggering impact on CSA survivors and methodological impact on research.

We did not interview female CSA survivors under the age of 40 or male CSA survivors. We hypothesise that the recommendation of compassionate care will still resonate with women under 40 since similar barriers and strategies to improve the cervical screening experience have been identified for this age group.[20] Male CSA survivors may have a different suite of barriers and facilitators to cancer screening, but there is evidence that they will also benefit from compassionate care.[25 47 48]

The role of sociodemographic, sociopolitical, cultural, substance use, mental health and post-traumatic stress disorder are important directions for future research not captured effectively during our investigation. Future research is also needed on quantifying how prevalent the perceptions presented here are among all CSA survivors and survivors of youth or adult sexual abuse and violence. Finally, another potential area of future research would be to conduct a similar qualitative study among women with and without a history of CSA to determine whether or not these are unique needs or concerns with this population.

The relationship with providers may be the most important determining factor in overcoming barriers to cancer screening among CSA survivors.[19 20 22 49] Provider awareness around why CSA survivors find cancer screenings difficult will enable providers to relate with understanding to their barriers. Compassionate care will reduce power inequalities and alleviate the environmental triggers associated with cancer screening.

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intellectual content; approved the final version to be published; and agree to be accountable for all aspects of the work, including ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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