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What Helps Survivors of Childhood Sexual Abuse Attend Cancer Screening? Qualitative Interview Study'

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ABSTRACT

Objective: The sexual abuse survivor population (Survivors) is substantial and Survivors have been identified as a population with low rates of breast, cervical and colon cancer screening participation. Our objective was to learn what helps Survivors get screened for breast, cervical and colon cancer.

Design: Qualitative study involving individual, semi-structured, in-depth key informant interviews conducted in January 2014. Thematic analysis was used to understand the relationship between childhood sexual abuse and cancer screening and to identify facilitators for screening.

Participants: Purposive sample of adult, female Survivors of childhood sexual abuse. The inclusion criteria were: being part of the Survivor community and being in a stable situation, where stable meant able to meet ones financial needs independently, able to maintain supportive relationships, having had therapy/psychotherapy to recover from past abuse, and currently living in a safe environment. Twelve Survivors were interviewed, ranging in age from early 40's to mid 70's. Saturation was reached after ten interviews.

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

Results: The core concept that emerged was that Survivor participation in cancer screening is supported most by compassionate care at every level of the health care experience including: the relationship with health care providers; appointment

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interactions; the cancer screening environment; and provider assumptions about patients.

Conclusions: Recommendations for delivering compassionate care include: building relationship; practicing 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. We further recommend practitioners use these recommendations as best practice standards regardless of patient disclosure of trauma history.

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Strengths and Limitations of this Study:

- A major strength of our study was having a Survivor of childhood sexual abuse actively participate in the development of research methods, data collection, data analysis and interpretation of study findings.
- We did not interview female Survivors under 40 years of age or male Survivors of childhood sexual abuse, although we hypothesize 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 odds of adult cancer diagnosis[1]. The reasons for this association are not fully understood; however, one possibility is that survivors of childhood sexual abuse (Survivors) are less likely to access preventative health care or participate in routine cancer screening programs[2-4]. Survivors have been identified as a population with low rates of breast[5 6], cervical[3-5 7-9] and colon[10] cancer screening participation[2]. This is understandable since these screening tests involve squeezing and penetrating the body’s most intimate sexual sites; those same sites that were physically traumatized for Survivors in childhood.

An estimated one in three girls and one in six boys experience sexual abuse during childhood[11], making the sexual abuse survivor population substantial[12]. A few studies have identified barriers to cervical cancer screening for Survivors, including not wanting to be touched in the pelvic area and dissociating areas of the body[2 8]. Fewer still have identified facilitators to cervical cancer screening, such as improving communication, safety, trust and sharing control[13]. There is a dearth of studies identifying barriers and facilitators to breast[5] or colon[10] cancer screening. Our objective was to learn what helps Survivors get screened for breast, cervical and colon cancer.

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METHODS

Survivors of childhood sexual abuse are vulnerable because of their history of abuse, trauma and exploitation. 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 Survivors interact with other members of the Survivor community, where relationship, trust, and rapport are more quickly established because of shared experience and mutual understanding. Therefore, our community partner (LN), who is also a Survivor of childhood sexual abuse, was the point person for recruitment and interviewed all participants.

We conducted individual, semi-structured, in-depth key informant interviews with Survivors of childhood sexual abuse in January 2014. Key informants were identified through existing community contacts and partnerships and approached for participation primarily by word of mouth. Existing community contacts and partnerships included Survivors known to our community partner, whom she had met through their mutual interest in participating in Survivor support groups or who had otherwise disclosed their history of sexual abuse to her in the context of sharing, support and healing stories. We maximized the breadth and diversity of Survivors interviewed by purposively sampling adult Survivors primarily from urban and rural Ontario but also from elsewhere in Canada and the United States. The inclusion criteria were: being part of the Survivor community and being in a stable situation, where stable meant able to meet ones

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financial needs independently, able to maintain supportive relationships, having had therapy/psychotherapy to recover from past abuse, and currently living in a safe environment.

Our community partner contacted Survivors to tell them about the project by email, phone, and chat room post. Those interested in participating contacted our community partner to schedule an interview. These key informants acted as seed participants in our sampling strategy. We continued with snowball sampling by asking seed participants at the end of the interview if there was someone else with whom we should talk; if they said yes, the participant was asked to pass our community partner's contact information on to that person so they could contact her about participating in the study.

Interviews with consenting interviewees was initiated and sustained with questions around: what seeing a health care provider was like, going (or not going) for cancer screening, what health care 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. Interviews took 45 minutes to a little over one hour to complete. Interviewees were given the option of having their interview over the phone or via on-line chat. One participant requested completing the interview by email. Participants were compensated for their time and knowledge.

For many Survivors, sexual abuse included video and/or audio recording for exploitation purposes, resulting in many Survivors being triggered by voice or image recording.

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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 conversation verbatim. Online chat interviews were already transcribed verbatim. All transcripts were anonymous. Field notes were taken to record both verbal and non-verbal insights, and salient points learned during interviews.

Throughout the interview, the 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 participants were emotionally stable and supported.

The interviewer had a follow-up conversation with each participant (member checking) one week after their interview to see if the interviewee had additional comments and was comfortable with the interview process and what came out during conversation. Preliminary results were also tested at this time. This follow-up conversation contributed to the rigor of our data collection and analysis, as well as provided an opportunity to check the emotional state of the participant and help resolve any unresolved issues raised by the research process.

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Thematic analysis[14] was used to understand the relationship between childhood sexual abuse and cancer screening and to identify facilitators for screening. Transcripts were read and coded simultaneously. Both researchers identified themes, then came together to share and discuss results and develop recommendations for increasing cancer screening among Survivors. Discrepancies were discussed until reconciled and interpretation and recommendations were agreed upon. Illustrative quotes are used to support themes, interpretations, and recommendations.

The University of Toronto Research Ethics Board approved this study.

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RESULTS

Twelve Survivors of childhood sexual abuse were interviewed in January 2014. Saturation was reached after ten interviews; however, two additional participants were interviewed to honor snowball referral and confirm saturation.

All participants were female. Their ages ranged from early 40’s to mid 70’s. Education ranged from limited formal education to post-graduate degrees. Survivors lived in rural (n=4), small town (n=5), and urban (n=2) communities in Canada (n=9) and the United States (n=3). Nine Survivors were mothers, two Survivors were First Nations, and two Survivors self-reported dissociative identity disorder.

Survivors wanted to be healthy and recognized the importance of personal agency in staying healthy, “We have to take responsibility for our health. I can tell the younger ones too. Some things aren’t comfortable but it’s for making us healthy” (Int 6).

Survivors identified several ways health care providers can help support patient efforts to “Be responsible for [our] own health” (Int 1). A common recommendation was health care providers recognizing the importance of 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)

The core concept that emerged was that Survivor participation in cancer screening is supported most by compassionate care. Compassionate care was needed at every level of the health care experience including: the relationship with health care providers; appointment interactions; the cancer screening environment; and provider assumptions about patients.

Relationship with Health Care Providers

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The relationship Survivors have with their doctor, nurse practitioner, lab technician and support staff has an effect on how they feel about health care and whether they seek cancer screening:

> “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)

> “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)

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Positive relationships and experiences with health care providers and the health care system had lasting effects for many Survivors, and they would use these positive relationships and experiences to counterbalance or even neutralize more negative medical experiences.

Appointment Interactions

The quality of the interaction with a health care provider during appointments was identified as a significant facilitator (or barrier) to cancer screening for Survivors. Recommended actions and interaction characteristics centered around the Provider-Survivor relationship and focused on the Provider being present and respectful; using motivational interviewing techniques; being mindful of body language; maintaining the Survivor's dignity; sharing control; and being "human."

Being present and respectful. Health care providers may have the deepest respect for their patients, but unless they communicate it, the patient is not likely to know it, especially patients who have been abused. Patients feel respected when they have their Provider's attention and can tell when the mind and attention of their health care provider is elsewhere:

> Int 7: "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.
>
> Interviewer: "How did you know she respects your dignity?
>
> Int 7: "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."

Listening, reassuring, being aware, and not rushing are simple ways to be present and respectful with patients, even if the appointment is brief:

> "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." (Int 10)

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Motivational Interviewing: Understanding a Survivor's Behaviour and Values to Evoke Behaviour Change. A Survivor's decision to participate in cancer screening can be impacted by the way their health care provider talks with them: "…it would be very helpful if they learned something about motivational interviewing" (Int 12). Motivational interviewing[15] is a therapeutic conversational style that focuses on the autonomy of the individual, collaboration between the individual and health care provider, and evoking sustainable behavior change in the individual. Motivational interviewing was developed to help alcoholics overcome their addiction[16] and has shown promise in supporting other positive behaviour change[17].

Being Mindful of Body Language. Body language communicates as much as (or more than) words and so impacts Health Care Provider-Survivor interactions. Survivors recommended being mindful of body language in terms of how body language can communicate both attention and intimidation (i.e. make sure body language is not intimidating) to facilitate feeling comfortable with cancer screening:

> Int 10: "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."

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Aggressive or sudden movements during physical examination or procedure by health care providers can be equally triggering for Survivors. One Survivor, for example, was startled and frightened when a phlebotomist grabbed her arm without warning. Survivors, like most patients, prefer not to be "treated like a piece of meat." (Int 2)

Maintaining Survivor Dignity. Survivors were not treated with dignity as children. Reminding Survivors they are worthy of honor or respect by treating them with dignity is not only empowering, but helps them get screened for cancer. Several Survivors recommended that simple ways to maintain patient dignity include: 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 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. Therefore, Survivors are more likely to become comfortable with screening if they feel they understand a procedure and share in the control of what is happening to them and their environment. Sharing control can be as simple as talking to patients in plain language and asking simple questions so they feel part of the conversation: "Just being asked these kinds of questions makes me feel more included" (Int 2).

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Sharing control is about having the patient feel they are an active and efficacious participant in the screening process. This can be done by offering patients 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 will increase 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 Survivors is by establishing a commonality: “we are both human.” Two of the simplest, most effective ways of relating on an equal basis are by sharing personal anecdotes and laughing. One Survivor described her favorite physician as: “She is not above sharing” (Int 9). Interviewees indicated that even a bit of humor can quickly improve health care interactions and transform the screening experience:

> “Humor helps me a lot. It's a sucky experience no matter how it happens and some is just the inherent nature of the test - the equipment is cold and you put an intimate/sensitive part of your body into it, to get squeezed beyond belief.” (Int 11)

> “If they have a sense of humor that would be nice too. But to be personable and a little light.” (Int 2)

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> "…if they kind of acknowledge that maybe using a sense of humor" (Int 9)

Our 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 our interviews.

The Cancer Screening Environment

"When they put that metal thing inside myself, it brings up a lot" (Int 4). Cancer screening tests can be triggering for Survivors in ways people without this history cannot fully predict or appreciate. As children, many 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 para-verbal insight into how post-traumatic stress and trauma of childhood sexual abuse can impact health care seeking and experience in adulthood. Keeping the physical environment comfortable and warm can help prevent triggers around being cold. Environment not only means the physical environment though, and also includes

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the cultural climate. Little things, like a smile or eye contact, can have a large positive impact:

> “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)

Assumptions

Some health care 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 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 indicated that health care providers deliver the best care when they treat everyone like they are a Survivor of sexual abuse:

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> "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)

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Other noteworthy observations

Many 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. Our interviews provided an opportunity to correct misinformation and provide sexual and reproductive health education. For instance, we addressed the radiation barrier by contextualizing the level of radiation exposure during mammography to everyday real world exposures, such as being less than a transcontinental flight, less than a dental exam, or less than standing beside a brick building.

Health care providers also have opportunity to educate patients during clinic visits and should not assume patients/clients know or correctly remember sexual and reproductive health information that will help them decide to participate in screening programs.

Health care providers can review how a patient can take care of their sexual health, including sexual health screening possibilities (sexually transmitted infections, cervical cancer, breast cancer, colon cancer) and a discussion of 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 interviewees have of the medical procedure - one that reiterates the abusive experience.

DISCUSSION

Our recommendations for increasing cancer screening among female Survivors of childhood sexual abuse are to deliver compassionate care by: building relationship; practicing 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. We further recommend practitioners 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, www.getscreened.ca, or supplementary files).

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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”[8] and developing interventions that reduce distress[10 18].

A major strength of our study was having a Survivor of childhood sexual abuse conduct the interviews and participate in the analysis. First, our community interviewer (LN) knew how to approach participants to ensure their safety and she was able to recognize 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 all Survivor voices had a chance to be heard. Having our community interviewer participate in the analysis helped identify and prioritize themes and recommendations that may have otherwise been disregarded or taken for granted.

The interview process itself turned out to be an example of what participants recommended, that is, using humor, paying attention, and sharing. A number of participants spoke about feeling very positive about the interview and their contribution.

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Specifically, one interviewee went to her doctor to discuss the human papilloma virus (HPV) vaccine because of what she learned during and following her interview. Another interviewee said 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.

We did not interview female Survivors under the age of 40 or male Survivors of childhood sexual abuse. We hypothesize that the recommendation of compassionate care will still resonate with both these groups[10 19]. It is very likely that male Survivors will have a different suite of barriers and facilitators to cancer screening and this signals a gap in the literature and thus our collective knowledge and understanding of how to best support male Survivors of childhood sexual abuse for cancer screening.

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Competing Interests: Both authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: DG received a research grant from Cancer Care Ontario to support the submitted work; LN was a paid from the Cancer Care Ontario grant to participate as a co-investigator and co-develop methods, conduct interviews with participants, assist in data analysis and recommendation development, and assist with dissemination activities; both authors have no financial relationships with any organizations that might have an interest in the submitted work in

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the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

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Author Contributions: DG and LN have both made substantial contributions to the conception or design of the work; the acquisition, analysis, or interpretation of data for the work; AND drafted the work, revised it critically for important intellectual content; AND 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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REFERENCES

1. Brown MJ, Thacker LR, Cohen SA. Association between adverse childhood experiences and diagnosis of cancer. PLoS One 2013;**8**(6):e65524 doi: 10.1371/journal.pone.0065524[published Online First: Epub Date]|.
2. Gesink D, Mihic A, Antal J, et al. Who are the under- and never-screened for cancer in Ontario: a qualitative investigation. BMC Public Health 2014;**14**:495 doi: 10.1186/1471-2458-14-495[published Online First: Epub Date]|.
3. Olesen SC, Butterworth P, Jacomb P, Tait RJ. Personal factors influence use of cervical cancer screening services: epidemiological survey and linked administrative data address the limitations of previous research. BMC health services research 2012;**12**:34 doi: 10.1186/1472-6963-12-34[published Online First: Epub Date]|.
4. Farley M, Golding JM, Minkoff JR. Is a history of trauma associated with a reduced likelihood of cervical cancer screening? The Journal of family practice 2002;**51**(10):827-31
5. Gandhi S, Rovi S, Vega M, Johnson MS, Ferrante J, Chen PH. Intimate partner violence and cancer screening among urban minority women. J Am Board Fam Med 2010;**23**(3):343-53 doi: 10.3122/jabfm.2010.03.090124[published Online First: Epub Date]|.
6. Watson-Johnson LC, Townsend JS, Basile KC, Richardson LC. Cancer screening and history of sexual violence victimization among U.S. adults. J Womens Health (Larchmt) 2012;**21**(1):17-25 doi: 10.1089/jwh.2011.2751[published Online First: Epub Date]|.
7. Ackerson K. A history of interpersonal trauma and the gynecological exam. Qual Health Res 2012;**22**(5):679-88 doi: 10.1177/1049732311424730[published Online First: Epub Date]|.
8. Cadman L, Waller J, Ashdown-Barr L, Szarewski A. Barriers to cervical screening in women who have experienced sexual abuse: an exploratory study. J Fam Plann Reprod Health Care 2012;**38**(4):214-20 doi: 10.1136/jfprhc-2012-100378[published Online First: Epub Date]|.
9. Leeners B, Stiller R, Block E, Gorres G, Imthurn B, Rath W. Effect of childhood sexual abuse on gynecologic care as an adult. Psychosomatics 2007;**48**(5):385-93 doi: 10.1176/appi.psy.48.5.385[published Online First: Epub Date]|.
10. Nicolai MP, Keller JJ, de Vries L, et al. The impact of sexual abuse in patients undergoing colonoscopy. PLoS One 2014;**9**(1):e85034 doi: 10.1371/journal.pone.0085034[published Online First: Epub Date]|.
11. Bagdley R. The Report of the Committee on Sexual Offences Against Children and Youth. Ottawa: Supply and Services Canada, 1984.
12. Trocme NM, MacLaurin BJ, Fallon BA, Daciuk JF, Tourigny M, Billingsley DA. Canadian Incidence Study of Reported Child Abuse and Neglect: methodology. Can J Public Health 2001;**92**(4):259-63
13. Kelly S. The effects of childhood sexual abuse on women's lives and their attitudes to cervical screening. J Fam Plann Reprod Health Care 2012;**38**(4):212-3 doi: 10.1136/jfprhc-2012-100418[published Online First: Epub Date]|.

For peer review only

14. Glaser BG. *Basics of grounded theory: emergence vs. forcing*. Mill Valley, CA: Sociology Press, 1992.
15. Miller WR, Rose GS. Toward a theory of motivational interviewing. Am Psychol 2009;**64**(6):527-37 doi: 10.1037/a0016830[published Online First: Epub Date]|.
16. Miller WR. Motivational interviewing: research, practice, and puzzles. Addict Behav 1996;**21**(6):835-42
17. Lundahl B, Moleni T, Burke BL, et al. Motivational interviewing in medical care settings: a systematic review and meta-analysis of randomized controlled trials. Patient Educ Couns 2013;**93**(2):157-68 doi: 10.1016/j.pec.2013.07.012[published Online First: Epub Date]|.
18. Weitlauf JC, Frayne SM, Finney JW, et al. Sexual violence, posttraumatic stress disorder, and the pelvic examination: how do beliefs about the safety, necessity, and utility of the examination influence patient experiences? J Womens Health (Larchmt) 2010;**19**(7):1271-80 doi: 10.1089/jwh.2009.1673[published Online First: Epub Date]|.
19. Davy E. The endoscopy patient with a history of sexual abuse: strategies for compassionate care. Gastroenterology nursing : the official journal of the Society of Gastroenterology Nurses and Associates 2006;**29**(3):221-5

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

No	Item	Guide questions/description	Details
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	LN
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	DG – PhD; LN – Hon BA, Survivor, Educator, Accomplished Novelist
3.	Occupation	What was their occupation at the time of the study?	DG – associate professor; LN – researcher, writer
4.	Gender	Was the researcher male or female?	Female
5.	Experience and training	What experience or training did the researcher have?	Both researchers have experience conducting interviews on sensitive sexual health topics
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	LN knew several participants prior to the study
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*	Purpose of the study was reviewed during the consent process
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	LN is a Survivor

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No	**Item**	**Guide questions/description**	**Details**
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Thematic analyisis
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Purposive and snowball
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*	Email, chat room post, word-of-mouth, participant referral
12.	Sample size	How many participants were in the study?	12
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	None
Setting			
14.	Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace*	On-line and over the phone
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	No
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	All participants were female Survivors in a stable situation and ranged in age (40's to 70's), education, geographic location
Data collection			
17.	Interview guide	Were questions, prompts,	See methods

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No	Item	Guide questions/description	Details
		guides provided by the authors? Was it pilot tested?	
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No, however, every participant was contacted one week after their interview for member checking
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	See methods
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Yes
21.	Duration	What was the duration of the interviews or focus group?	Approximately one hour each
22.	Data saturation	Was data saturation discussed?	Yes
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	See methods
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Two
25.	Description of the coding tree	Did authors provide a description of the coding tree?	See Results
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Themes derived from data
27.	Software	What software, if applicable, was used to manage the data?	No software was used
28.	Participant checking	Did participants provide feedback on the findings?	Yes
Reporting			
29.	Quotations	Were participant	Yes

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No	Item	Guide questions/description	Details
	presented	quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g. participant number*	
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes, see Results
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes, see Results

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

No	Item	Guide questions/description	Details
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	LN
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	DG – PhD; LN – Hon BA, Survivor, Educator, Accomplished Novelist
3.	Occupation	What was their occupation at the time of the study?	DG – associate professor; LN – researcher, writer
4.	Gender	Was the researcher male or female?	Female
5.	Experience and training	What experience or training did the researcher have?	Both researchers have experience conducting interviews on sensitive sexual health topics
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	LN knew several participants prior to the study
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*	Purpose of the study was reviewed during the consent process
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	LN is a Survivor
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Thematic analyisis
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Purposive and snowball
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*	Email, chat room post, word-of-mouth, participant referral
12.	Sample size	How many participants were in the study?	12

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No	Item	Guide questions/description	Details
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	None
Setting			
14.	Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace*	On-line and over the phone
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	No
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	All participants were female Survivors in a stable situation and ranged in age (40's to 70's), education, geographic location
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	See methods
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No, however, every participant was contacted one week after their interview for member checking
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	See methods
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Yes
21.	Duration	What was the duration of the interviews or focus group?	Approximately one hour each
22.	Data saturation	Was data saturation discussed?	Yes
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	See methods
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Two
25.	Description of the coding tree	Did authors provide a description of the coding tree?	See Results
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Themes derived from data
27.	Software	What software, if applicable, was used to manage the data?	No software was used
28.	Participant checking	Did participants provide feedback on the findings?	Yes
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes /	Yes

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No	Item	Guide questions/description	Details
		findings? Was each quotation identified? e*.g. participant number*	
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes, see Results
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes, see Results

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Compassionate Care Can Help Childhood Sexual Abuse Survivors Attend Cancer Screening. A Qualitative Interview Study.

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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 under 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 health care providers improve cancer screening participation.

Design: A qualitative study involving individual, semi-structured, 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. Twelve Survivors were interviewed. Ages ranged from early 40's to mid 70's. Descriptive saturation was reached after ten 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 United States.

Results: The core concept that emerged was that compassionate care at every level of the health care experience could improve cancer screening participation. Main themes included: desire for holistic care; unique needs of patients with dissociative identity

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disorder; the relationship with health care providers; appointment interactions; the cancer screening environment; and provider assumptions about patients.

Conclusions: Compassionate care can be delivered by: building relationship; practicing 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 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 Survivors under 40 years of age or male Survivors of childhood sexual abuse, although we hypothesize that the recommendation of compassionate care will resonate with both these groups.

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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], as well as significantly increased odds of adult cancer diagnosis[2-4]. The reasons for this latter association are complex and not fully understood[5]; however, one possibility is that survivors of childhood sexual abuse (CSA) are less likely to access preventative health care or participate in routine cancer screening programs[6-8]. CSA survivors have been identified as a population with low rates of breast[9 10], cervical[7-9 11-13] and colon[14] cancer screening participation[6]. This is understandable since these screening tests involve squeezing and penetrating the body's most intimate sexual sites; those same sites that were physically traumatized for CSA survivors.

It is very challenging to accurately estimate the CSA population given variability in definitions of CSA and difficulties measuring CSA[15 16]. 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[16]. The evidence also indicates that CSA cases are significantly unreported suggesting that the CSA survivor population is substantial[17]. 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.

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A few studies have identified barriers to cervical cancer screening for Survivors, including not wanting to be touched in the pelvic area and dissociating areas of the body[6 12]. Fewer studies have identified facilitators to cervical cancer screening, such as improving communication, safety, trust and sharing control[18]. There is a dearth of studies identifying barriers and facilitators to breast[9] or colon[14] 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 health care providers improve cancer screening participation.

METHODS

We used a community based participatory research (CBPR) approach[19-22] to conduct cancer screening research with CSA survivors. CSA survivors are a hidden, hard-to-reach population because of shame, guilt, 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 rigor in the development of sensitive and supportive interview methods; increase access, uptake, recruitment and participation in interviews; strengthen the accuracy, rigor, and reliability of our data analysis and interpretation; aide knowledge translation; and maximize participant support and community benefit[22-25].

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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 recognized 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”[26] and is often associated with CSA[26 27].

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

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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 50 years old and older because of the standard screening age requirements for breast and colon cancer are 50 years old and older. However, we also interviewed CSA survivors in their 40's 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, semi-structured, in-depth interviews (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[28]. Participants were asked to talk about their experience seeking medical care in general and then specifically about breast, cervical and colon cancer screening as relevant to them. Participants were also asked what health care providers can do to make it easier to get screened and if there was anything else they wanted to say or

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thought we should know. Outsider researchers reviewed interview questions, probes and flow before the interview guide was finalized.

Interviews took 45 minutes to a little over one hour to complete. Participants were given the option of having their interview over the phone or via on-line chat. One participant requested completing 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 [29] so 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 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 learned during interviews.

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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 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 (e.g. 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 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 one week after their interview to see if the interviewee had additional comments and was comfortable with the interview process and what came out during conversation. Preliminary data analysis results were also reviewed at this time (member checking). This follow-up conversation contributed to the rigor of our data collection and analysis. It also provided an opportunity to check the emotional state of the participant and help

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resolve any unresolved issues raised by the research process. No unresolved issues remained.

Thematic analysis[30 31] was used to identify and describe CSA survivor perspectives on cancer screening and potential facilitators for screening. We increased rigor, 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 organized 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 one perspective did not dominate interpretation of the results and to ensure 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 upon. Descriptive saturation was confirmed during thematic analysis when no new codes, categories or themes emerged from the data. Fieldnotes were used to aid interpretation of themes. Illustrative quotes are used to support themes, interpretations, and recommendations.

The University of Toronto Research Ethics Board approved this study.

RESULTS

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

All participants were female. Their ages ranged from early 40's to mid 70's: three in their 40's, six in their 50's, two in their 60's and one in her 70's. Education ranged from limited formal education to post-graduate degrees. CSA survivors lived in rural (n=4), small town (n=5), and urban (n=3) communities in Canada (n=9) and the United States (n=3). Nine CSA survivors were mothers and two were First Nations. Three participants disclosed having dissociative identity disorder (DID) and had more than one personality participate in the interview, though it is likely that more than two participants were DID since is highly stigmatized and even debated in the psychiatric world[26] 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.

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Survivors wanted to be healthy and recognized the importance of personal agency in staying healthy. Survivors identified several ways health care providers can 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 is supported most by compassionate care. Compassionate care means providers relating to CSA survivor, and really all patients, on a human level, in understanding, empathizing and mitigating potential sources of suffering. Compassionate care is the overarching term we use to summarize the themes and sub-themes from our analysis, including: the desire for holistic care; the unique needs of CSA survivors with dissociative identity disorder; the patient - health care provider relationship; appointment interactions; the cancer screening environment; and provider assumptions about patients. Each theme is described in detail below.

Desire for Holistic Care

A common theme that CSA survivors used to exemplify the concept of compassionate care was holistic care that balances physical, mental, emotional and spiritual health:

> “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)

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The Unique Needs of CSA Survivors with Dissociative Identity Disorder

We found DID could affect cancer screening both in terms of accessing and participating in screening programs. One participant shared: “We have to take responsibility for our health. I can tell the younger ones too. Some things aren’t comfortable but it’s 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[26] is not helping people with multiple personalities (multiples) access health care services or get the care they need. The debate can impact the way some doctors interact with DID patients and thus undermining the DID experience and trust. As one DID participant 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, health care 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

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> appointment in a young state. He treated me as usual, his tone changed in a gentle way." (Int 6)

Doctor awareness of the mental and emotional state of the patient, changes in state, and providing compassionate care can facilitate present and future cancer screening participation.

Relationship with Health Care Providers

The relationship CSA survivors have with their doctor, nurse practitioner, lab technician and support staff has an effect on how they feel about health care and whether they seek cancer screening:

> "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)

> "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)

Positive relationships and experiences with health care providers and the health care system had lasting effects for many CSA survivors, and they would use these positive relationships and experiences to counterbalance or even neutralize more negative medical experiences.

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Appointment Interactions

The quality of the interaction with a health care provider during appointments was identified as a significant facilitator (or barrier) to cancer screening for CSA survivors. Recommended actions and interaction characteristics centered around the provider-survivor relationship and focused on the provider being mentally present and respectful; using motivational interviewing techniques; being mindful of body language; maintaining the Survivor's dignity; sharing control; and being "human".

Being mentally present and respectful. Health care providers may have the deepest respect for their patients, but unless they communicate it, the patient is not likely to know it, especially patients who have been abused. Patients feel respected when they have their Provider's attention and can tell when the mind and attention of their health care provider is elsewhere:

> Int 7: "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.
>
> Interviewer: "How did you know she respects your dignity?
>
> Int 7: "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."

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Listening, reassuring, being aware, and not rushing are simple ways to be present and respectful with patients, even if the appointment is brief:

> "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." (Int 10)

Motivational Interviewing: Understanding a CSA Survivor's Behaviour and Values to Evoke Behaviour Change. A CSA survivor's decision to participate in cancer screening can be impacted by the way their health care provider talks with them: "…it would be very helpful if they learned something about motivational interviewing" (Int 12). Motivational interviewing[32] is a therapeutic conversational style that focuses on the autonomy of the individual, collaboration between the individual and health care provider, and evoking sustainable behavior change in the individual. Motivational interviewing was developed to help alcoholics overcome their addiction[33] and has shown promise in supporting other positive behaviour change[34].

Being Mindful of Body Language. Body language communicates as much as (or more than) words and so impacts provider-survivor interactions. CSA survivors recommended being mindful of body language in terms of how body language can communicate both attention and intimidation (i.e. make sure body language is not intimidating) to facilitate feeling comfortable with cancer screening:

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> Int 10: "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."

Aggressive or sudden movements during physical examination or procedure by health care 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 they are worthy of honor and respect by treating them with dignity is not only empowering, but helps them get screened for cancer. Several CSA survivors recommended that simple ways to maintain patient dignity include: 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

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their consent or knowledge of what was happening to them. Therefore, CSA survivors are more likely to become comfortable with screening if they feel they understand a procedure and share in the control of what is happening to them and their environment. Sharing control can be as simple as talking to patients in plain language and asking simple questions so they feel part of the conversation: “Just being asked these kinds of questions makes me feel more included” (Int 2).

Sharing control is about having the patient feel they are an active and efficacious participant in the screening process. This can be done by offering patients 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 will 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 is by establishing a commonality: “we are both human.” Two of the simplest, most effective ways of relating on an equal basis are by sharing personal anecdotes and laughing. As one CSA survivor described, “She is not above sharing” (Int 9). Interviewees indicated that even a bit of humor can quickly improve health care interactions and transform the screening experience:

> “Humor helps me a lot. It's a sucky experience no matter how it happens and some is just the inherent nature of the test - the equipment is cold and you put an

For peer review only

> intimate/sensitive part of your body into it, to get squeezed beyond belief." (Int 11)

> "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)

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

"When they put that metal thing inside myself, it brings up a lot" (Int 4). 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)

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The choppy disconnected sentences used to communicate this recommendation lends additional para-verbal insight into how post-traumatic stress and the trauma of CSA can impact health care seeking and experiences in adulthood. Keeping the physical environment comfortable and warm can help prevent triggers around being cold. Environment not only means the physical environment though, and also includes the cultural climate. Little things, like a smile or eye contact, can have a large positive impact:

> “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)

Female provider preference was common among participants.

Assumptions

Some health care 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

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main difference in reaction was grounded in why the 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 indicated that health care providers deliver the best care when they treat everyone like they are a sexual abuse survivor:

> “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)

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. Our interviews provided an opportunity to correct misinformation and provide sexual and reproductive health education. For instance, we addressed the radiation barrier by contextualizing the level of radiation exposure during mammography to everyday real world exposures, such as being less than a

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transcontinental flight, less than a dental exam, or less than standing beside a brick building.

Health care providers also have opportunities to educate patients during clinic visits and should not assume patients/clients know or correctly remember sexual and reproductive health information that will help them decide to participate in screening programs. Health care providers can review how a patient can take care of their sexual health, including sexual health screening possibilities (sexually transmitted infections, cervical cancer, breast cancer, colon cancer) and a discussion of 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 interviewees have of the medical procedure - one that reiterates the abusive experience.

Finally, structural barriers were identified by women living in isolated areas:

> "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."

DISCUSSION

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CSA survivors described compassionate care being needed at every level of the health care experience including: when working with patients who have dissociative identity disorder; the relationship with health care providers; appointment interactions; the cancer screening environment; and provider assumptions about patients. Compassionate care can be delivered by: providing holistic care; building relationship; practicing 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 health care 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, www.getscreened.ca, or supplementary files).

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”[12] and developing interventions that reduce distress[14 35].

Our findings also highlight the unique needs of CSA survivors with DID who may have to balance internal competing perspectives on screening and may arrive to an appointment in a dissociated or younger state.

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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 recognize 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 all CSA survivor voices had a chance to be heard. Having our community partner participate in the analysis helped identify and prioritize 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 DID participants in a way that obtained different points of view from those parts (identities) who presented. Her experience and sensitivity towards DID helped DID participants, 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-

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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 humor, 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 human papilloma virus (HPV) vaccine because of what she learned during and following her interview. Another interviewee said 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 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 online chat were recorded verbatim through the written record.

We did not interview female CSA survivors under the age of 40 or male CSA survivors. We hypothesize 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[12]. 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 [14 36 37].

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The role of socio-demographic, socio-political, 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.

The relationship with providers may be the most important determining factor in overcoming barriers to cancer screening among CSA survivors[12 38-40]. 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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We thank the women who shared their stories and insights with us for this project.

Competing Interests: Both authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: DG received a research grant from Cancer Care Ontario to support the submitted work; LN was paid from the Cancer Care Ontario grant to participate as a co-investigator and co-develop methods, conduct interviews with participants, assist in data analysis and recommendation development, and assist with dissemination activities; both authors have no financial relationships with

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any organizations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

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Author Contributions: DG and LN have both made substantial contributions to the conception or design of the work; the acquisition, analysis, or interpretation of data for the work; AND drafted the work, revised it critically for important intellectual content; AND 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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REFERENCES

1. Maniglio R. The impact of child sexual abuse on health: a systematic review of reviews. Clinical psychology review 2009;**29**(7):647-57 doi: 10.1016/j.cpr.2009.08.003[published Online First: Epub Date]|.

2. Brown MJ, Thacker LR, Cohen SA. Association between adverse childhood experiences and diagnosis of cancer. PLoS One 2013;**8**(6):e65524 doi: 10.1371/journal.pone.0065524[published Online First: Epub Date]|.

3. Bellis MA, Hughes K, Leckenby N, Hardcastle KA, Perkins C, Lowey H. Measuring mortality and the burden of adult disease associated with adverse childhood experiences in England: a national survey. J Public Health (Oxf) 2014 doi: 10.1093/pubmed/fdu065[published Online First: Epub Date]|.

4. Kelly-Irving M, Lepage B, Dedieu D, et al. Childhood adversity as a risk for cancer: findings from the 1958 British birth cohort study. BMC Public Health 2013;**13**:767 doi: 10.1186/1471-2458-13-767[published Online First: Epub Date]|.

5. Kelly-Irving M, Mabile L, Grosclaude P, Lang T, Delpierre C. The embodiment of adverse childhood experiences and cancer development: potential biological mechanisms and pathways across the life course. Int J Public Health 2013;**58**(1):3-11 doi: 10.1007/s00038-012-0370-0[published Online First: Epub Date]|.

6. Gesink D, Mihic A, Antal J, et al. Who are the under- and never-screened for cancer in Ontario: a qualitative investigation. BMC Public Health 2014;**14**:495 doi: 10.1186/1471-2458-14-495[published Online First: Epub Date]|.

For peer review only

7. Olesen SC, Butterworth P, Jacomb P, Tait RJ. Personal factors influence use of cervical cancer screening services: epidemiological survey and linked administrative data address the limitations of previous research. BMC health services research 2012;**12**:34 doi: 10.1186/1472-6963-12-34[published Online First: Epub Date]|.

8. Farley M, Golding JM, Minkoff JR. Is a history of trauma associated with a reduced likelihood of cervical cancer screening? The Journal of family practice 2002;**51**(10):827-31

9. Gandhi S, Rovi S, Vega M, Johnson MS, Ferrante J, Chen PH. Intimate partner violence and cancer screening among urban minority women. J Am Board Fam Med 2010;**23**(3):343-53 doi: 10.3122/jabfm.2010.03.090124[published Online First: Epub Date]|.

10. Watson-Johnson LC, Townsend JS, Basile KC, Richardson LC. Cancer screening and history of sexual violence victimization among U.S. adults. J Womens Health (Larchmt) 2012;**21**(1):17-25 doi: 10.1089/jwh.2011.2751[published Online First: Epub Date]|.

11. Ackerson K. A history of interpersonal trauma and the gynecological exam. Qual Health Res 2012;**22**(5):679-88 doi: 10.1177/1049732311424730[published Online First: Epub Date]|.

12. Cadman L, Waller J, Ashdown-Barr L, Szarewski A. Barriers to cervical screening in women who have experienced sexual abuse: an exploratory study. J Fam Plann Reprod Health Care 2012;**38**(4):214-20 doi: 10.1136/jfprhc-2012-100378[published Online First: Epub Date]|.

For peer review only

13. Leeners B, Stiller R, Block E, Gorres G, Imthurn B, Rath W. Effect of childhood sexual abuse on gynecologic care as an adult. Psychosomatics 2007;**48**(5):385-93 doi: 10.1176/appi.psy.48.5.385[published Online First: Epub Date]|.

14. Nicolai MP, Keller JJ, de Vries L, et al. The impact of sexual abuse in patients undergoing colonoscopy. PLoS One 2014;**9**(1):e85034 doi: 10.1371/journal.pone.0085034[published Online First: Epub Date]|.

15. Collin-Vezina D, De La Sablonniere-Griffin M, Palmer AM, Milne L. A preliminary mapping of individual, relational, and social factors that impede disclosure of childhood sexual abuse. Child abuse & neglect 2015 doi: 10.1016/j.chiabu.2015.03.010[published Online First: Epub Date]|.

16. Martin EK, Silverstone PH. How Much Child Sexual Abuse is "Below the Surface," and Can We Help Adults Identify it Early? Front Psychiatry 2013;**4**:58 doi: 10.3389/fpsyt.2013.00058[published Online First: Epub Date]|.

17. Trocme NM, MacLaurin BJ, Fallon BA, Daciuk JF, Tourigny M, Billingsley DA. Canadian Incidence Study of Reported Child Abuse and Neglect: methodology. Can J Public Health 2001;**92**(4):259-63

18. Kelly S. The effects of childhood sexual abuse on women's lives and their attitudes to cervical screening. J Fam Plann Reprod Health Care 2012;**38**(4):212-3 doi: 10.1136/jfprhc-2012-100418[published Online First: Epub Date]|.

19. Israel BA, Schulz AJ, Parker EA. *Methods in Community-Based Participatory Research for Health*. San Francisco, CA: Jossey-Bass, 2005.

20. Subrahmanian K, Petereit DG, Kanekar S, et al. Community-based participatory development, implementation, and evaluation of a cancer screening educational

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intervention among American Indians in the Northern Plains. Journal of cancer education : the official journal of the American Association for Cancer Education 2011;**26**(3):530-9 doi: 10.1007/s13187-011-0211-5[published Online First: Epub Date]|.

21. Wallerstein N, Duran B. Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. American Journal of Public Health 2010;**100 Suppl 1**:S40-6 doi: 10.2105/AJPH.2009.184036[published Online First: Epub Date]|.

22. Jagosh J, Macaulay AC, Pluye P, et al. Uncovering the benefits of participatory research: implications of a realist review for health research and practice. Milbank Q 2012;**90**(2):311-46 doi: 10.1111/j.1468-0009.2012.00665.x[published Online First: Epub Date]|.

23. Urquhart R, Grunfeld E, Jackson L, Sargeant J, Porter GA. Cross-disciplinary research in cancer: an opportunity to narrow the knowledge-practice gap. Curr Oncol 2013;**20**(6):e512-21 doi: 10.3747/co.20.1487[published Online First: Epub Date]|.

24. Flanagan SM, Hancock B. 'Reaching the hard to reach'--lessons learned from the VCS (voluntary and community Sector). A qualitative study. BMC health services research 2010;**10**:92 doi: 10.1186/1472-6963-10-92[published Online First: Epub Date]|.

25. Bonevski B, Randell M, Paul C, et al. Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially

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disadvantaged groups. BMC Med Res Methodol 2014;**14**:42 doi: 10.1186/1471-2288-14-42[published Online First: Epub Date]|.

26. Dorahy MJ, Brand BL, Sar V, et al. Dissociative identity disorder: An empirical overview. Aust N Z J Psychiatry 2014;**48**(5):402-17 doi: 10.1177/0004867414527523[published Online First: Epub Date]|.

27. Sar V. The many faces of dissociation: opportunities for innovative research in psychiatry. Clin Psychopharmacol Neurosci 2014;**12**(3):171-9 doi: 10.9758/cpn.2014.12.3.171[published Online First: Epub Date]|.

28. Kovach M. *Indigenous Methodologies: Characteristics, Conversations and Contexts*. Toronto: University of Toronto Press, 2009.

29. Hettema J, Steele J, Miller WR. Motivational interviewing. Annu Rev Clin Psychol 2005;**1**:91-111 doi: 10.1146/annurev.clinpsy.1.102803.143833[published Online First: Epub Date]|.

30. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology 2006;**3**(2):77-101

31. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol 2013;**13**:117 doi: 10.1186/1471-2288-13-117[published Online First: Epub Date]|.

32. Miller WR, Rose GS. Toward a theory of motivational interviewing. Am Psychol 2009;**64**(6):527-37 doi: 10.1037/a0016830[published Online First: Epub Date]|.

33. Miller WR. Motivational interviewing: research, practice, and puzzles. Addict Behav 1996;**21**(6):835-42

For peer review only

34. Lundahl B, Moleni T, Burke BL, et al. Motivational interviewing in medical care settings: a systematic review and meta-analysis of randomized controlled trials. Patient Educ Couns 2013;**93**(2):157-68 doi: 10.1016/j.pec.2013.07.012[published Online First: Epub Date]|.

35. Weitlauf JC, Frayne SM, Finney JW, et al. Sexual violence, posttraumatic stress disorder, and the pelvic examination: how do beliefs about the safety, necessity, and utility of the examination influence patient experiences? J Womens Health (Larchmt) 2010;**19**(7):1271-80 doi: 10.1089/jwh.2009.1673[published Online First: Epub Date]|.

36. Davy E. The endoscopy patient with a history of sexual abuse: strategies for compassionate care. Gastroenterology nursing : the official journal of the Society of Gastroenterology Nurses and Associates 2006;**29**(3):221-5

37. Gallo-Silver L, Anderson CM, Romo J. Best clinical practices for male adult survivors of childhood sexual abuse: "do no harm". Perm J 2014;**18**(3):82-7.

38. Maar M, Burchell A, Little J, et al. A qualitative study of provider perspectives of structural barriers to cervical cancer screening among first nations women. Women's health issues : official publication of the Jacobs Institute of Women's Health 2013;**23**(5):e319-25.

39. Ogedegbe G, Cassells AN, Robinson CM, et al. Perceptions of barriers and facilitators of cancer early detection among low-income minority women in community health centers. J Natl Med Assoc 2005;**97**(2):162-70

For peer review only

40. Bukowska-Durawa A, Luszczynska A. Cervical cancer screening and psychosocial barriers perceived by patients. A systematic review. Contemp Oncol (Pozn) 2014;**18**(3):153-9.

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Appendix I: Interview Guide

PART I: Informed Consent for Interviews

What's this Project About?
The purpose of this project is to increase cancer screening among individuals who have a history of sexual abuse. To do this, we need to understand what would improve cancer screening among individuals who have been sexually abused. We will use what we learn to develop and pilot an educational video targeting health care providers from the medical community on the needs of abuse survivors in relation to cancer screening.

Why Me?
We would like to talk with you because you are an abuse survivor.

What do you want from me?
We would like your guidance and insight on what would make it easier to get screened for breast, cervical and/or colon cancer. Phone interviews will run 45 minutes to a little over an hour if we get chatty.

What are the Risks?
The interview will focus on present experiences with the medical system and cancer screening. However, the conversation could touch on past memories of abuse, which could bring up old feelings, which may or may not be distressing. You will be supported through all emotions experienced through conversation and interaction. If you feel sadness or sorrow, we will ask you how you want to proceed (e.g. sit quietly while they work through the emotion, take a break, continue, or finish up early). If you feel you need additional support, we will cover the cost of a session with your therapist. You may also refuse to participate or withdraw from this project at any time. You will still be compensated. We will retain any information you have given to us up to that point. No knowledge or information you share with us will be associated with your identity. Results from all interviews will be aggregated so no one, other than the interviewer, will know what you communicated.

What are the Benefits?
The direct benefits are having your voice heard, increasing the awareness and understanding of abuse in relation to cancer screening, having an influence on cancer screening programs, practice, and policy in Ontario. Sometimes participating in studies also gives one the opportunity to learn from others and clarify our own knowing and thinking, especially as we talk about things. The community will also benefit from your knowledge, which will lead to improved cancer screening.

Do you have any questions?

Would you like to participate? **Yes** **No**

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PART II: INTERVIEW QUESTIONS

Guide/Process:

First, visit to ease into conversation and develop communication style.

Second, introduce study and review consent form.

Third, ask questions.

Throughout the interview, feel free to:
- Empower participant through the value of their participation,
- Use personal sharing (as helpful) to build rapport and trust,
- Provide support and validation to help participant through emotions that arise during interview,
- Pay attention throughout to how participant is feeling
- Check in at end to make sure participant is ok and supported

Questions:

1. What is seeing a doctor, nurse or lab tech like for you?
    - If respondents say it's hard, express understanding. "Yes, that's hard for a lot of people who've been sexually abused. What do you think that doctors and nurses need to know?"
2. Have you gone for cancer screening?
    - Ask about each of breast, cervical and colon cancer as appropriate.
    - If yes, what helps you go? What could be improved?
    - If no, what stops you from going? What would help you? What could be improved?
3. Is there's anything else that doctors or lab techs could do to make it easier?
    - If the person says, “oh I can't imagine anything it's so hard”, then say, “what makes it hard/for you?”

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- In the study so far, sexual abuse has been brought up as a barrier to screening for breast, cervical and colon cancer à most personal sites for screening à what would help abuse survivors get screened
- Do you think a self-collected HPV test would be helpful if it was available?

4. Is there anything else you want to say or we should know?

Thank you for your time and insights. They are greatly appreciated.

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829 **APPENDIX II: Consolidated criteria for reporting qualitative studies (COREQ): 32-**
830 **item checklist**

No	**Item**	**Guide questions/description**	**Details**
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	LN
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	DG – PhD; LN – Hon BA, Survivor, Educator, International Author and Advocate, Moderator of Survivors' Chat
3.	Occupation	What was their occupation at the time of the study?	DG – associate professor; LN – researcher, writer
4.	Gender	Was the researcher male or female?	Female
5.	Experience and training	What experience or training did the researcher have?	Both researchers have experience conducting interviews on sensitive sexual health topics
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	LN knew several participants prior to the study
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e*.g. personal goals, reasons for doing the research*	Purpose of the study was reviewed during the consent process
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions,*	LN is a Survivor

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No	Item	Guide questions/description	Details
		reasons and interests in the research topic	
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Thematic analyisis
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Purposive and snowball
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*	Email, messaging in survivors' boards, word-of-mouth, participant referral
12.	Sample size	How many participants were in the study?	12
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	None
Setting			
14.	Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace*	On-line and over the phone
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	No
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	All participants were female Survivors in a stable situation and ranged in age (40's to 70's), education, geographic location

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No	**Item**	**Guide questions/description**	**Details**
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	See methods
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No, however, every participant was contacted one week after their interview for member checking
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	See methods
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Yes
21.	Duration	What was the duration of the interviews or focus group?	Approximately one hour each
22.	Data saturation	Was data saturation discussed?	Yes
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	See methods
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Two
25.	Description of the coding tree	Did authors provide a description of the coding tree?	See Results
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Themes derived from data
27.	Software	What software, if applicable, was used to manage the data?	No software was used
28.	Participant checking	Did participants provide feedback on the findings?	Yes

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No	Item	Guide questions/description	Details
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g. participant number*	Yes
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes, see Results
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes, see Results

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

No	Item	Guide questions/description	Details
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	LN
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	DG – PhD; LN – Hon BA, Survivor, Educator, Accomplished Novelist
3.	Occupation	What was their occupation at the time of the study?	DG – associate professor; LN – researcher, writer
4.	Gender	Was the researcher male or female?	Female
5.	Experience and training	What experience or training did the researcher have?	Both researchers have experience conducting interviews on sensitive sexual health topics
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	LN knew several participants prior to the study
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*	Purpose of the study was reviewed during the consent process
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	LN is a Survivor
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Thematic analyisis
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Purposive and snowball
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*	Email, chat room post, word-of-mouth, participant referral
12.	Sample size	How many participants were in the study?	12

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No	Item	Guide questions/description	Details
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	None
Setting			
14.	Setting of data collection	Where was the data collected? e.g. *home, clinic, workplace*	On-line and over the phone
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	No
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	All participants were female Survivors in a stable situation and ranged in age (40's to 70's), education, geographic location
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	See methods
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No, however, every participant was contacted one week after their interview for member checking
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	See methods
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Yes
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23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	See methods
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Two
25.	Description of the coding tree	Did authors provide a description of the coding tree?	See Results
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Themes derived from data
27.	Software	What software, if applicable, was used to manage the data?	No software was used
28.	Participant checking	Did participants provide feedback on the findings?	Yes
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes /	Yes

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No	Item	Guide questions/description	Details
		findings? Was each quotation identified? e*.g. participant number*	
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes, see Results
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes, see Results

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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 under 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 health care providers improve cancer screening participation.

Design: A pragmatic constructivist qualitative study involving individual, semi-structured, 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. Twelve Survivors were interviewed. Ages ranged from early 40's to mid 70's. Descriptive saturation was reached after ten 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 United States.

Results: The core concept that emerged was that compassionate care at every level of the health care experience could improve cancer screening participation. Main themes

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included: desire for holistic care; unique needs of patients with dissociative identity disorder; the patient-health care provider relationship; appointment interactions; the cancer screening environment; and provider assumptions about patients.

Conclusions: Compassionate care can be delivered by: building relationship; practicing 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.

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Strengths and Limitations of this Study:

- A major strength of our study was taking a community based research approach and having a 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 under 40 years of age or male CSA survivors, although we hypothesize 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 responsible for cervical cancer[13] earlier in life and more often, less likely to access preventative health care, or less likely to participate in routine cancer screening programs 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 traumatized for CSA survivors.

It is very challenging to accurately estimate the CSA population given variability in definitions of CSA and difficulties 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

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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 health care 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, 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 rigor in the development of sensitive and supportive interview methods; increase access, uptake, recruitment and participation in interviews; strengthen the

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accuracy, rigor, and reliability of our data analysis and interpretation; aide knowledge translation; and maximize 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 recognized 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 were contacted by our community partner through her pre-existing network as the moderator of an online CSA support group and internationally recognized CSA author and advocate. Survivors were contacted by email, phone, and chat room post to tell them about the project. We maximized the breadth and diversity of participants by purposively sampling CSA survivors with varying cancer screening habits (never-, under-, or regularly- screened), socioeconomic status,

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and education levels, as well as being from urban or rural Ontario, or elsewhere in Canada or the United States. 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 50 years old and older because of the standard screening age requirements for breast and colon cancer are 50 years old and older. However, we also interviewed CSA survivors in their 40's 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, semi-structured, in-depth interviews (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 seeking medical care

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in general and then specifically about breast, cervical and colon cancer screening as relevant to them. Participants were also asked what health care 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. Outsider researchers reviewed interview questions, probes and flow before the interview guide was finalized.

Interviews took 45 minutes to a little over one hour to complete. Participants were given the option of having their interview over the phone or via on-line chat. One participant requested completing 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 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 conversation verbatim. Online chat interviews were already transcribed verbatim through the written

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record. All transcripts were anonymous. Field notes were taken to record both verbal and non-verbal insights, and salient points learned 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 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 (e.g. 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 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 one week after their interview to see if the interviewee had additional comments and was comfortable with the interview process and what came out during conversation.

For peer review only

Preliminary data analysis results were also reviewed at this time (member checking). This follow-up conversation contributed to the rigor 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 rigor, 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 organized 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 one perspective did not dominate interpretation of the results and to ensure 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 upon. Descriptive saturation was confirmed during thematic analysis when no new codes, categories or themes emerged from the data. Fieldnotes were used to aid interpretation of themes. Illustrative quotes are used to support themes, interpretations, and recommendations.

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The University of Toronto Research Ethics Board approved this study.

RESULTS

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

All participants were female. Their ages ranged from early 40's to mid 70's: three in their 40's, six in their 50's, two in their 60's and one in her 70's. Education ranged from limited formal education to post-graduate degrees. CSA survivors lived in rural (n=4), small town (n=5), and urban (n=3) communities in Canada (n=9) and the United States (n=3). Nine CSA survivors were mothers and two were First Nations. Three participants disclosed having dissociative identity disorder (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 stigmatized 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

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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 recognized the importance of personal agency in staying healthy. Survivors identified several ways health care 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, empathizing and mitigating potential sources of suffering. Compassionate care is the overarching term we use to summarize the themes and sub-themes from our analysis, including: the desire for holistic care; the unique needs of CSA survivors with dissociative identity disorder; the patient - health care provider relationship; appointment interactions; the cancer screening environment; and provider assumptions about patients. Each theme is described in detail below.

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 health care providers were more holistic in their approach, attending to the emotional or psychological supports needed to overcome the anxiety of cancer

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screening. They also suggested that helping CSA survivors recognize 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 Dissociative Identity Disorder

We found DID could affect cancer screening both in terms of accessing and participating in screening programs. One participant shared: “We have to take responsibility for our health. I can tell the younger ones too. Some things aren’t comfortable but it’s 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 health care services or get the care they need. The debate can impact the way some doctors interact with DID patients and thus undermine the experience and trust. As one DID participant 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)

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Furthermore, health care 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 Health Care Providers

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

Appointment Interactions

The quality of the interaction with a health care provider during appointments was identified as a significant facilitator (or barrier) to cancer screening for CSA survivors.

For peer review only

Recommended actions and interaction characteristics centered 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. Health care providers may have the deepest respect for their patients, but unless they communicate it, the patient is not likely to know it, especially patients who have been abused. Patients felt respected when they had their provider's attention and could tell when their health care provider's mind and attention was elsewhere (table 1). Participants suggested health care 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.

Communication styles. Several CSA survivors said their decision to participate in cancer screening was impacted by the way their health care provider talked with them and suggested that humour could help relieve some of the anxiety of screening (table 1). They also suggested that: "…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 health care provider, and evoking sustainable behavior change in the individual. Motivational interviewing was developed to help alcoholics overcome their addiction[44] and has shown promise in supporting other positive behaviour change[45].

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Being Mindful of Body Language. Body language communicates as much as (or more than) words and so impacts provider-survivor interactions. CSA survivors recommended health care providers be mindful of body language in terms of how body language can communicate both attention and intimidation (i.e. 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 health care 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 they are worthy of honor and respect by treating them with dignity is not only empowering, but 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

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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 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 humor could quickly improve health care 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

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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 para-verbal insight into how post-traumatic stress and the trauma of CSA can impact health care 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 health care providers struggle with whether to ask patients if they have experienced sexual abuse. We found that while some survivors appreciate being asked

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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 health care providers deliver the best care when they treat everyone like they are a sexual abuse survivor (table 1).

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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.

Health care providers may have opportunities to educate patients during clinic visits and should not assume patients/clients know or correctly remember sexual and reproductive health information that might help them decide to participate in screening programs. Clinic visits present an opportunity to review how to take care of ones 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 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.”

DISCUSSION

CSA survivors described compassionate care being beneficial at every level of the health care experience including: when working with patients who have dissociative identity disorder; the patient-health care 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 relationship; practicing respect; focusing attention on the patient; not rushing the appointment; keeping the environment positive and comfortable; maintaining patient

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dignity; sharing control whenever possible; explaining procedures; and using laughter to reduce power imbalances through shared humanity. We further suggest health care 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, www.getscreened.ca, or supplementary files). The intention was for this video to be a resource for: educational institutions (medical training programs, nursing programs, allied health programs) to train new health care providers, health care facilities to train new or existing staff, continuing education credits for health care providers already delivering care to CSA survivors, or simply for health care 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 cancer screening participation could be improved with interventions and outreach efforts that provide psycho-education 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.

For peer review only

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]. 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 programs.

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 recognize 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

For peer review only

> 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 all CSA survivor voices had a chance to be heard. Having our community partner participate in the analysis helped identify and prioritize 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 DID participants in a way that obtained different points of view from those parts (identities) who presented. Her experience and sensitivity towards DID helped DID participants, 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 humor, 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 human papilloma virus (HPV) vaccine because of what she learned during and following her interview. Another interviewee said 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.

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The absence of 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 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 methodologic impact on research.

We did not interview female CSA survivors under the age of 40 or male CSA survivors. We hypothesize 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 socio-demographic, socio-political, 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

For peer review only

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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For peer review only

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REFERENCES

1. Maniglio R. The impact of child sexual abuse on health: a systematic review of reviews. Clinical psychology review 2009;**29**(7):647-57 doi: 10.1016/j.cpr.2009.08.003[published Online First: Epub Date]|.

2. Bernier MJ, Hebert M, Collin-Vezina D. Dissociative symptoms over a year in a sample of sexually abused children. Journal of trauma & dissociation : the official journal of the International Society for the Study of Dissociation 2013;**14**(4):455-72 doi: 10.1080/15299732.2013.769478[published Online First: Epub Date]|.

3. Collin-Vezina D, Cyr M, Pauze R, McDuff P. The role of depression and dissociation in the link between childhood sexual abuse and later parental practices. Journal of trauma & dissociation : the official journal of the International Society for the Study of Dissociation 2005;**6**(1):71-97 doi: 10.1300/J229v06n01_05[published Online First: Epub Date]|.

4. Collin-Vezina D, Hebert M. Comparing dissociation and PTSD in sexually abused school-aged girls. The Journal of nervous and mental disease 2005;**193**(1):47-52

5. Ginzburg K, Koopman C, Butler LD, et al. Evidence for a dissociative subtype of post-traumatic stress disorder among help-seeking childhood sexual abuse survivors. Journal of trauma & dissociation : the official journal of the International Society for the Study of Dissociation 2006;**7**(2):7-27 doi: 10.1300/J229v07n02_02[published Online First: Epub Date]|.

6. Mueller-Pfeiffer C, Moergeli H, Schumacher S, et al. Characteristics of child maltreatment and their relation to dissociation, posttraumatic stress symptoms, and depression in adult psychiatric patients. The Journal of nervous and mental

For peer review only

disease 2013;**201**(6):471-7 doi: 10.1097/NMD.0b013e3182948096[published Online First: Epub Date]|.

7. Price C. Dissociation reduction in body therapy during sexual abuse recovery. Complementary therapies in clinical practice 2007;**13**(2):116-28 doi: 10.1016/j.ctcp.2006.08.004[published Online First: Epub Date]|.

8. Rivera-Velez GM, Gonzalez-Viruet M, Martinez-Taboas A, Perez-Mojica D. Post-traumatic stress disorder, dissociation, and neuropsychological performance in Latina victims of childhood sexual abuse. Journal of child sexual abuse 2014;**23**(1):55-73 doi: 10.1080/10538712.2014.864746[published Online First: Epub Date]|.

9. Brown MJ, Thacker LR, Cohen SA. Association between adverse childhood experiences and diagnosis of cancer. PLoS One 2013;**8**(6):e65524 doi: 10.1371/journal.pone.0065524[published Online First: Epub Date]|.

10. Bellis MA, Hughes K, Leckenby N, Hardcastle KA, Perkins C, Lowey H. Measuring mortality and the burden of adult disease associated with adverse childhood experiences in England: a national survey. J Public Health (Oxf) 2014 doi: 10.1093/pubmed/fdu065[published Online First: Epub Date]|.

11. Kelly-Irving M, Lepage B, Dedieu D, et al. Childhood adversity as a risk for cancer: findings from the 1958 British birth cohort study. BMC Public Health 2013;**13**:767 doi: 10.1186/1471-2458-13-767[published Online First: Epub Date]|.

12. Kelly-Irving M, Mabile L, Grosclaude P, Lang T, Delpierre C. The embodiment of adverse childhood experiences and cancer development: potential biological mechanisms and pathways across the life course. Int J Public Health

For peer review only

2013;**58**(1):3-11 doi: 10.1007/s00038-012-0370-0[published Online First: Epub Date]|.

13. Bosch FX, de Sanjose S. The epidemiology of human papillomavirus infection and cervical cancer. Dis Markers 2007;**23**(4):213-27

14. Gesink D, Mihic A, Antal J, et al. Who are the under- and never-screened for cancer in Ontario: a qualitative investigation. BMC Public Health 2014;**14**:495 doi: 10.1186/1471-2458-14-495[published Online First: Epub Date]|.

15. Olesen SC, Butterworth P, Jacomb P, Tait RJ. Personal factors influence use of cervical cancer screening services: epidemiological survey and linked administrative data address the limitations of previous research. BMC health services research 2012;**12**:34 doi: 10.1186/1472-6963-12-34[published Online First: Epub Date]|.

16. Farley M, Golding JM, Minkoff JR. Is a history of trauma associated with a reduced likelihood of cervical cancer screening? The Journal of family practice 2002;**51**(10):827-31

17. Weitlauf JC, Frayne SM, Finney JW, et al. Sexual violence, posttraumatic stress disorder, and the pelvic examination: how do beliefs about the safety, necessity, and utility of the examination influence patient experiences? J Womens Health (Larchmt) 2010;**19**(7):1271-80 doi: 10.1089/jwh.2009.1673[published Online First: Epub Date]|.

18. Weitlauf JC, Jones S, Xu X, et al. Receipt of cervical cancer screening in female veterans: impact of posttraumatic stress disorder and depression. Women's health issues : official publication of the Jacobs Institute of Women's Health

For peer review only

2013;**23**(3):e153-9 doi: 10.1016/j.whi.2013.03.002[published Online First: Epub Date]|.

19. Bukowska-Durawa A, Luszczynska A. Cervical cancer screening and psychosocial barriers perceived by patients. A systematic review. Contemp Oncol (Pozn) 2014;**18**(3):153-9 doi: 10.5114/wo.2014.43158[published Online First: Epub Date]|.

20. Cadman L, Waller J, Ashdown-Barr L, Szarewski A. Barriers to cervical screening in women who have experienced sexual abuse: an exploratory study. J Fam Plann Reprod Health Care 2012;**38**(4):214-20 doi: 10.1136/jfprhc-2012-100378[published Online First: Epub Date]|.

21. Kelly S. The effects of childhood sexual abuse on women's lives and their attitudes to cervical screening. J Fam Plann Reprod Health Care 2012;**38**(4):212-3 doi: 10.1136/jfprhc-2012-100418[published Online First: Epub Date]|.

22. Maar M, Burchell A, Little J, et al. A qualitative study of provider perspectives of structural barriers to cervical cancer screening among first nations women. Women's health issues : official publication of the Jacobs Institute of Women's Health 2013;**23**(5):e319-25 doi: 10.1016/j.whi.2013.06.005[published Online First: Epub Date]|.

23. Gandhi S, Rovi S, Vega M, Johnson MS, Ferrante J, Chen PH. Intimate partner violence and cancer screening among urban minority women. J Am Board Fam Med 2010;**23**(3):343-53 doi: 10.3122/jabfm.2010.03.090124[published Online First: Epub Date]|.

For peer review only

24. Watson-Johnson LC, Townsend JS, Basile KC, Richardson LC. Cancer screening and history of sexual violence victimization among U.S. adults. J Womens Health (Larchmt) 2012;**21**(1):17-25 doi: 10.1089/jwh.2011.2751[published Online First: Epub Date]|.

25. Nicolai MP, Keller JJ, de Vries L, et al. The impact of sexual abuse in patients undergoing colonoscopy. PLoS One 2014;**9**(1):e85034 doi: 10.1371/journal.pone.0085034[published Online First: Epub Date]|.

26. Collin-Vezina D, De La Sablonniere-Griffin M, Palmer AM, Milne L. A preliminary mapping of individual, relational, and social factors that impede disclosure of childhood sexual abuse. Child abuse & neglect 2015 doi: 10.1016/j.chiabu.2015.03.010[published Online First: Epub Date]|.

27. Martin EK, Silverstone PH. How Much Child Sexual Abuse is "Below the Surface," and Can We Help Adults Identify it Early? Front Psychiatry 2013;**4**:58 doi: 10.3389/fpsyt.2013.00058[published Online First: Epub Date]|.

28. Trocme NM, MacLaurin BJ, Fallon BA, Daciuk JF, Tourigny M, Billingsley DA. Canadian Incidence Study of Reported Child Abuse and Neglect: methodology. Can J Public Health 2001;**92**(4):259-63

29. Creswell JS. *Research Design: Qualitative, Quantitative and Mixed Methods Approaches. 4rd Edition.* Thousand Oaks, CA: Sage Publication, 2014.

30. Israel BA, Schulz AJ, Parker EA. *Methods in Community-Based Participatory Research for Health*. San Francisco, CA: Jossey-Bass, 2005.

31. Subrahmanian K, Petereit DG, Kanekar S, et al. Community-based participatory development, implementation, and evaluation of a cancer screening educational

For peer review only

intervention among American Indians in the Northern Plains. Journal of cancer education : the official journal of the American Association for Cancer Education 2011;**26**(3):530-9 doi: 10.1007/s13187-011-0211-5[published Online First: Epub Date]|.

32. Wallerstein N, Duran B. Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. American Journal of Public Health 2010;**100 Suppl 1**:S40-6 doi: 10.2105/AJPH.2009.184036[published Online First: Epub Date]|.

33. Jagosh J, Macaulay AC, Pluye P, et al. Uncovering the benefits of participatory research: implications of a realist review for health research and practice. Milbank Q 2012;**90**(2):311-46 doi: 10.1111/j.1468-0009.2012.00665.x[published Online First: Epub Date]|.

34. Urquhart R, Grunfeld E, Jackson L, Sargeant J, Porter GA. Cross-disciplinary research in cancer: an opportunity to narrow the knowledge-practice gap. Curr Oncol 2013;**20**(6):e512-21 doi: 10.3747/co.20.1487[published Online First: Epub Date]|.

35. Flanagan SM, Hancock B. 'Reaching the hard to reach'--lessons learned from the VCS (voluntary and community Sector). A qualitative study. BMC health services research 2010;**10**:92 doi: 10.1186/1472-6963-10-92[published Online First: Epub Date]|.

36. Bonevski B, Randell M, Paul C, et al. Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially

For peer review only

disadvantaged groups. BMC Med Res Methodol 2014;**14**:42 doi: 10.1186/1471-2288-14-42[published Online First: Epub Date]|.

37. Dorahy MJ, Brand BL, Sar V, et al. Dissociative identity disorder: An empirical overview. Aust N Z J Psychiatry 2014;**48**(5):402-17 doi: 10.1177/0004867414527523[published Online First: Epub Date]|.
38. Sar V. The many faces of dissociation: opportunities for innovative research in psychiatry. Clin Psychopharmacol Neurosci 2014;**12**(3):171-9 doi: 10.9758/cpn.2014.12.3.171[published Online First: Epub Date]|.
39. Kovach M. *Indigenous Methodologies: Characteristics, Conversations and Contexts*. Toronto: University of Toronto Press, 2009.
40. Hettema J, Steele J, Miller WR. Motivational interviewing. Annu Rev Clin Psychol 2005;**1**:91-111 doi: 10.1146/annurev.clinpsy.1.102803.143833[published Online First: Epub Date]|.
41. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology 2006;**3**(2):77-101
42. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol 2013;**13**:117 doi: 10.1186/1471-2288-13-117[published Online First: Epub Date]|.
43. Miller WR, Rose GS. Toward a theory of motivational interviewing. Am Psychol 2009;**64**(6):527-37 doi: 10.1037/a0016830[published Online First: Epub Date]|.
44. Miller WR. Motivational interviewing: research, practice, and puzzles. Addict Behav 1996;**21**(6):835-42

For peer review only

45. Lundahl B, Moleni T, Burke BL, et al. Motivational interviewing in medical care settings: a systematic review and meta-analysis of randomized controlled trials. Patient Educ Couns 2013;**93**(2):157-68 doi: 10.1016/j.pec.2013.07.012[published Online First: Epub Date]|.

46. Barrera M, Calderon L, Bell V. The cognitive impact of sexual abuse and PTSD in children: a neuropsychological study. Journal of child sexual abuse 2013;**22**(6):625-38 doi: 10.1080/10538712.2013.811141[published Online First: Epub Date]|.

47. Davy E. The endoscopy patient with a history of sexual abuse: strategies for compassionate care. Gastroenterology nursing : the official journal of the Society of Gastroenterology Nurses and Associates 2006;**29**(3):221-5

48. Gallo-Silver L, Anderson CM, Romo J. Best clinical practices for male adult survivors of childhood sexual abuse: "do no harm". Perm J 2014;**18**(3):82-7 doi: 10.7812/TPP/14-009[published Online First: Epub Date]|.

49. Ogedegbe G, Cassells AN, Robinson CM, et al. Perceptions of barriers and facilitators of cancer early detection among low-income minority women in community health centers. J Natl Med Assoc 2005;**97**(2):162-70

For peer review only

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

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	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)

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	"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)

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)

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Appendix I: Interview Guide

PART I: Informed Consent for Interviews

What's this Project About?

The purpose of this project is to increase cancer screening among individuals who have a history of sexual abuse. To do this, we need to understand what would improve cancer screening among individuals who have been sexually abused. We will use what we learn to develop and pilot an educational video targeting health care providers from the medical community on the needs of abuse survivors in relation to cancer screening.

Why Me?

We would like to talk with you because you are an abuse survivor.

What do you want from me?

We would like your guidance and insight on what would make it easier to get screened for breast, cervical and/or colon cancer. Phone interviews will run 45 minutes to a little over an hour if we get chatty.

What are the Risks?

The interview will focus on present experiences with the medical system and cancer screening. However, the conversation could touch on past memories of abuse, which could bring up old feelings, which may or may not be distressing. You will be supported through all emotions experienced through conversation and interaction. If you feel

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sadness or sorrow, we will ask you how you want to proceed (e.g. sit quietly while they work through the emotion, take a break, continue, or finish up early). If you feel you need additional support, we will cover the cost of a session with your therapist. You may also refuse to participate or withdraw from this project at any time. You will still be compensated. We will retain any information you have given to us up to that point. No knowledge or information you share with us will be associated with your identity. Results from all interviews will be aggregated so no one, other than the interviewer, will know what you communicated.

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What are the Benefits?

The direct benefits are having your voice heard, increasing the awareness and understanding of abuse in relation to cancer screening, having an influence on cancer screening programs, practice, and policy in Ontario. Sometimes participating in studies also gives one the opportunity to learn from others and clarify our own knowing and thinking, especially as we talk about things. The community will also benefit from your knowledge, which will lead to improved cancer screening.

Do you have any questions?

Would you like to participate? **Yes** **No**

PART II: INTERVIEW QUESTIONS

Guide/Process:

First, visit to ease into conversation and develop communication style.

Second, introduce study and review consent form.

Third, ask questions.

Throughout the interview, feel free to:

- Empower participant through the value of their participation,
- Use personal sharing (as helpful) to build rapport and trust,
- Provide support and validation to help participant through emotions that arise during interview,
- Pay attention throughout to how participant is feeling
- Check in at end to make sure participant is ok and supported

Questions:

1. What is seeing a doctor, nurse or lab tech like for you?
    - If respondents say it's hard, express understanding. "Yes, that's hard for a lot of people who’ve been sexually abused. What do you think that doctors

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and nurses need to know?"

2. Have you gone for cancer screening?
    - Ask about each of breast, cervical and colon cancer as appropriate.
    - If yes, what helps you go? What could be improved?
    - If no, what stops you from going? What would help you? What could be improved?
3. Is there's anything else that doctors or lab techs could do to make it easier?
    - If the person says, “oh I can't imagine anything it's so hard”, then say, “what makes it hard/for you?”
    - In the study so far, sexual abuse has been brought up as a barrier to screening for breast, cervical and colon cancer à most personal sites for screening à what would help abuse survivors get screened
    - Do you think a self-collected HPV test would be helpful if it was available?
4. Is there anything else you want to say or we should know?

Thank you for your time and insights. They are greatly appreciated.

For peer review only

846 **APPENDIX II: Consolidated criteria for reporting qualitative studies (COREQ): 32-**
847 **item checklist**

No	**Item**	**Guide questions/description**	**Details**
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	LN
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	DG – PhD; LN – Hon BA, Survivor, Educator, International Author and Advocate, Moderator of Survivors' Chat
3.	Occupation	What was their occupation at the time of the study?	DG – associate professor; LN – researcher, writer

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No	**Item**	**Guide questions/description**	**Details**
4.	Gender	Was the researcher male or female?	Female
5.	Experience and training	What experience or training did the researcher have?	Both researchers have experience conducting interviews on sensitive sexual health topics
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	LN knew several participants prior to the study
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*	Purpose of the study was reviewed during the consent process
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g.	LN is a Survivor

For peer review only

No	Item	Guide questions/description	Details
		Bias, assumptions, reasons and interests in the research topic	
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Thematic analyisis
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Purposive and snowball

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No	**Item**	**Guide questions/description**	**Details**
11.	Method of approach	How were participants approached? e.g. *face-to-face, telephone, mail, email*	Email, messaging in survivors' boards, word-of-mouth, participant referral
12.	Sample size	How many participants were in the study?	12
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	None
Setting			
14.	Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace*	On-line and over the phone
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	No
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	All participants were female Survivors in a stable situation and ranged in age (40's to

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No	Item	Guide questions/description	Details
			70's), education, geographic location
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	See methods
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No, however, every participant was contacted one week after their interview for member checking
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	See methods
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Yes
21.	Duration	What was the duration of the interviews or focus	Approximately one hour each

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No	Item	Guide questions/description	Details
		group?	
22.	Data saturation	Was data saturation discussed?	Yes
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	See methods
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Two
25.	Description of the coding tree	Did authors provide a description of the coding tree?	See Results
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Themes derived from data
27.	Software	What software, if applicable, was used to	No software was used

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No	Item	Guide questions/description	Details
		manage the data?	
28.	Participant checking	Did participants provide feedback on the findings?	Yes
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. *participant number*	Yes
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes, see Results
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes, see Results

848

For peer review only

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

No	Item	Guide questions/description	Details
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	LN
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	DG – PhD; LN – Hon BA, Survivor, Educator, Accomplished Novelist
3.	Occupation	What was their occupation at the time of the study?	DG – associate professor; LN – researcher, writer
4.	Gender	Was the researcher male or female?	Female
5.	Experience and training	What experience or training did the researcher have?	Both researchers have experience conducting interviews on sensitive sexual health topics
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	LN knew several participants prior to the study
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*	Purpose of the study was reviewed during the consent process
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	LN is a Survivor
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Thematic analyisis
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Purposive and snowball
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*	Email, chat room post, word-of-mouth, participant referral
12.	Sample size	How many participants were in the study?	12

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No	**Item**	**Guide questions/description**	**Details**
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	None
Setting			
14.	Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace*	On-line and over the phone
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	No
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	All participants were female Survivors in a stable situation and ranged in age (40's to 70's), education, geographic location
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	See methods
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No, however, every participant was contacted one week after their interview for member checking
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	See methods
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Yes
21.	Duration	What was the duration of the interviews or focus group?	Approximately one hour each
22.	Data saturation	Was data saturation discussed?	Yes
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	See methods
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Two
25.	Description of the coding tree	Did authors provide a description of the coding tree?	See Results
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Themes derived from data
27.	Software	What software, if applicable, was used to manage the data?	No software was used
28.	Participant checking	Did participants provide feedback on the findings?	Yes
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes /	Yes

For peer review only

No	Item	Guide questions/description	Details
		findings? Was each quotation identified? e.*g. participant number*	
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes, see Results
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes, see Results

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