

# **KAIRON PROJECT: Assessing the Role of Expressive Arts in Community-Based Breast Cancer Support Systems in the Niagara Region**

Research Report Written for the Canadian Breast Cancer Foundation – February 2007

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## **Introduction: Project Background and Goals**

This research report constitutes one outcome of a 12 month community health promotion planning and assessment project funded by the Canadian Breast Cancer Foundation. The Kairon Project was designed specifically to explore the role of expressive arts in the healing journey of women living with breast cancer in the Niagara region. The project's overall goal is to gauge the specific needs, interests, and preferences of these women for expressive arts in community-based support programming.

In a 2004 Breast Cancer Information Dissemination study conducted by OBCIEP, focus groups with Niagara women living with breast cancer identified the most effective methods of making appropriate breast cancer information available to them and the most useful community-based support programs. Regarding support programs, many women were interested in exploring the role of expressive arts - particularly art, theatre and story-telling productions - as community-based participatory projects that enabled them to express and understand their experiences with breast cancer, to support each other as they learn to live with breast cancer, and to communicate their experiences to the wider community. The Kairon Project focuses on this interest in more detail to develop better understandings of (a) women's experiences with and definitions of expressive arts, (b) their ideas about what support benefits expressive arts can provide, (c) their concerns about program access and appropriate participatory strategies, and (d) their thematic preferences for expressive arts workshops.

Our project consists of two main components: focus group interviews and exploratory expressive arts workshops. This report deals solely with focus group participants who may not have joined exploratory workshops. Selections of the interviews conducted with workshop participants are available on the DVD that has been submitted alongside this report.

Considering the project goals outlined above, the research team addressed the following research questions:

- What are the support needs and preferences of women living with breast cancer in the Niagara region?
- What impressions and experiences have women had with expressive arts, either informally or through a formalised support-programming framework?
- How do women living with breast cancer define expressive arts?
- What support benefits have they received from participating in expressive arts activities in the past? What support benefits do they expect to receive in future community-based expressive arts workshops and productions?

- How do women living with breast cancer want to access expressive arts programs? Where?
- In what types of expressive arts program are women interested in participating? Why?
- How can women living with breast cancer participate in developing expressive arts programming?

These research questions guided the design of focus group interviews, as well as the questions we asked of participants in those interviews.

## **My Role**

As a professor of Sociology at Brock University, I joined the Kairon Project research team, with Dr. David Fancy and Ms. Karin Perry, as a project member, coordinating team member, and, most importantly for this report, as the coordinator for the qualitative research component of the project. It was my responsibility to establish and confirm research questions, develop appropriate methodologies, design interview questions, moderate focus group interviews, interpret the data collected, and write this final report. I was also responsible for training other research team members as co-moderators of focus group interviews and for applying for ethics approval from the Brock University Research Ethics Board (REB) as we were conducting research with human participants.

I was invited to participate in this research project due to my related skills and experience. First, as a social science academic, I have been trained in qualitative research design and data collection techniques, which I also teach to undergraduate students. Second, my previous research experience has included designing, moderating, and interpreting focus group interviews, along with more traditional ethnographic projects.

## **Research Participants**

Over the course of nine months we conducted four focus group interviews with a diverse group of women who are living with breast cancer in the Niagara Region. Overall, 31 women participated in the study. These women range widely in age (from early 30s to late 70s), cultural background, linguistic group, and geographical location within the region. All but four women are currently using some sort of support service in the Niagara Region. Participants are at every stage of post-diagnosis.

### Focus Groups

- 1) Interview with the Francophone community: nine women (conducted in French)
- 2) Interview with the Aboriginal community: four women
- 3) Interview with women from geographically marginalised regions: nine women
- 4) Interview with women living in the city of St. Catharines: nine women

In our initial proposal for the project, we planned to conduct six focus group interviews, each with eight participants. Five specific communities were targeted: Francophone, Aboriginal, new immigrant, geographically marginalised, and mainstream St. Catharines. The sixth focus group

was to be comprised of eight women who had already participated in one of the previous five interviews, to allow for cross-community discussion of the seven research questions listed above. We had trouble recruiting eight Aboriginal participants, but decided to proceed with four, and unfortunately got no response from new immigrants. Also, some focus group participants got involved with other project workshops, with the result that we had difficulty finding enough women with enough time to participate in yet another interview, our sixth.

The following procedures guided the four focus group interviews:

- the research provided participants with confidentiality: their names do not appear on the transcripts or in this final report
- focus group interviews were approximately 90 minutes in length
- focus groups were audiotaped: audiotapes were transcribed verbatim for analysis
- participants were recruited through the assistance of breast cancer community organisations such as New Beginnings, Centre de Santé Communautaire, the Breast Cancer Research and Education Fund, Women's Place, Well Spring, Community Care, and the Canadian Cancer Society
- each participant received \$50 to attend the interview

## **Emerging Themes from Focus Group Interviews**

In every focus group we conducted, participants stressed that the topic of expressive arts support was personally significant, because it affected the quality of their everyday lives and the healing process that is a vital component of living with breast cancer. This insight is supported by women's ability to readily identify art forms they enjoy and engage in every day. Participants also recognised that there are both passive and active ways to engage with expressive arts, which can be done alone or in conjunction with others. The vast majority of women participated wholeheartedly in the interviews, and stressed that "time flew by" as they tried to communicate their complex relationship to the topic. Their behaviour, as well as their words, suggests that they are invested in the issues raised, as well as any future programs that result for the research.

### A. Women's Experience with Expressive Arts

Perhaps surprisingly, research participants readily identified a wide variety of expressive arts forms they currently access and enjoy in their everyday lives. This list includes:

- knitting and crocheting
- sewing: dressmaking, quilting, crafts
- gardening
- theatre
- movies
- drawing and painting
- walking, running and biking in nature; exercise more generally
- cooking
- puzzles and card games
- music: singing, playing an instrument, listening

- dancing
- stained glass
- viewing art at a museum
- reading
- writing/journaling
- drumming
- meditation and guided visualisation
- chanting
- PowWows
- basket making
- sharing circles
- jewellery making

As I have already noted, participants stressed that expressive arts are already an important aspect of their lives, for reasons I discuss in detail below. One woman explains that she enjoys “all forms of expression. I have to be creative with myself everyday, because there’s nothing else out there that can satisfy us to the same extent.”

#### B. Women’s Experience with Breast Cancer Support Programs in the Niagara Region

While most participants had accessed some form of breast cancer support program in the region, many were dissatisfied with some aspect of their experience with those programs. Indeed, several women in the Francophone interview found available programs unsatisfactory in dealing with even the most basic aspects of their experience of breast cancer: diagnosis and treatment. They described how their experiences of diagnosis and treatment have shaped how they have subsequently experienced living with breast cancer. This preoccupation with the trauma of diagnosis and treatment is evident in the following sequential transcript excerpt. The moderator attempts, several times, to move the conversation from a discussion of the experience of diagnosis and treatment and the lack of support they received around that issue in community cancer programs to a consideration of how expressive arts might have been a successful tool in dealing with the problem, without success:

Moderator: “During the period of diagnosis and treatment, what kinds of expressive arts do you think might have been useful in relieving some of your stress?”

Participant 1: “There was also some health insurance problem with my carrier, which added stress to being diagnosed.”

Participant 2: “I had to be extra careful [when I was treated for breast cancer], because I also had blood problems.”

Participant 3: “I started genetic testing in Hamilton after being diagnosed. I had to sign waivers for insurance purposes too.”

Participant 4: “They told me that breast cancer was related to colon cancer, which is what my father died of!”

Participants' experience of diagnosis and treatment remains a salient preoccupation, which gives us the sense that this aspect of living with breast cancer needs to be given prominence in every support program initiative.

The participants in both the St. Catharines and geographically marginalised group had accessed a range of support programs, including those mentioned by their oncologists and the information brochures available in the oncologists' offices. Many also immediately contacted the Canadian Cancer Society. As one participant explains, "The oncologist doesn't have time to tell you anything. So, it was kind of like 'Search it out on our own.' So, I drove over to the Canadian Cancer Society. They were really helpful, because I had no idea. Did I need a wig? They helped me, gave me soothing tapes, rainforest sounds and such. That just sort of calmed me down at home." A woman who lives in Port Colbourne confessed "I was never aware that there were any programs until I had to go to an oncologist at the Welland hospital, and I picked up a little booklet there. And I found out about the programs in St. Catharines. I went there and enjoyed it very much. But I wish it had been available to me *from the start.*"

Most women usually come to know about Well Spring and the Living Well Clinic in St. Catharines, even when they live out of town. Their experiences there were overwhelmingly positive, as one St. Catharines resident explains:

The really great thing about the Living Well Clinic is that it's a social gathering place for women... It's a place where you go and feel really great. It's not a 'down' kind of place; people are positive and learn a lot from each other. And I think that was a HUGE help to me. My son said 'You're a lot better when you go there.' And I knew that he was talking about mentally that I'm nicer at home because I laughed so much there.

The emphasis she places on 'feeling really great,' laughing, and being positive at cancer support programs explains why many women are dissatisfied with what they called 'traditional confessional support groups.'

These support programs can be a problem, according to our participants, because they often focus on disease and trauma, inside of living. As the following quotations show, the women in our study largely avoid traditional support groups that encourage women with breast cancer to talk about their experiences with the disease:

I couldn't stand the stories. Inside, my heart was so sad, listening to those women. I thought, 'You know, I'm going to die.' I knew it wasn't healthy for me.

I was miserable. I walked away every time thinking 'OK, when am I going to die?' But the Living Well Clinic made me laugh. And we do artistic things as well.

It doesn't necessarily help you to hear somebody else's story, nor someone to hear yours. That's the problem with traditional support groups, I found. I wouldn't go to a support group, because I need to focus on my *recovery*, not my illness. So, support groups aren't that good, whereas more of a social, relaxing, and creative thing, where you focus on recovery, is better. For me it worked.

You're there to have a laugh, have a good time, partake in a sauna or some beauty treatment. You're not there to discuss your breast cancer. You're there to have fun and enjoy an evening.

If people are discussing their breast cancer, the focus becomes cancer and it's depressing. But if you shift the focus to living well, getting better, living forever beautifully, you're shifting your focus positively.

These women seem to be interested in support programming that focuses on living (well and beautifully), laughing, and being positive in a friendly and creative social environment.

While women who live in St. Catharines tend to be well aware of available support programs, those living in the south of the Niagara Region often aren't. A Port Colbourne resident contends "There needs to be greater awareness of services, everyone who provides them in this community. Perhaps someone who helps put a package together for a newly diagnosed person. It's devastating." This kind of support information package would have helped some women learn about the locally organised Living with Cancer support group in Port Colbourne. When this program was mentioned during one focus group, this conversation ensued:

Participant 1: "OK, so how come I never knew about it, and I live in Wainfleet?"

Participant 2: "Because advertising is so expensive we can't begin to advertise. It kind of goes through word of mouth."

Participant 3: "I've been wanting to come to the group, but I have other medical issues and unfortunately, by the time evening rolls around, I'm done in... I just don't have a lot of energy sometimes to attend, but I *know* I would get a lot out of it. An afternoon would be much better for me."

But awareness of support programs is not the only problem for women who live in outlying areas. For many women who live in Port Colbourne, for example, having to travel to St. Catharines to access the Living Well Clinic or Well Spring is another obstacle:

I don't even like going to St. Catharines. The driving turns me off. And you know, more and more everything is focussed in St. Catharines. I just say 'Forget it!' But local things, I'm interested.

Having some support that's sort of locally situated, where people can get access to it, is important.

I like that there are things like meditation and yoga offered through those programs. And I know that it's not that far to St. Catharines. But I still feel like I have to ask for a ride and be a bother... In town here there's really nothing much you can do.

Women living in Welland feel much the same way:

It would have been nice if there was even one person from the cancer society that stopped by and said 'Do you want to talk?' In Welland, you do get the care you

need, but that's where it stops. Absolutely *nothing* extra, you're on your own. So I found that was definitely lacking in Welland, not the treatment, but when it comes to support there isn't anything. You always have to travel to St. Catharines, and that's a problem.

The cost associated with other welcome 'therapies' accessed through these support programs - including Reiki, saunas, and massages - is also prohibitive for some women. According to an Aboriginal participant, "I think a sauna and massage and whatever else is fine, but when you're on a fixed income because you're on disability, the money is just not there. We're not all gifted with the wealth of our grandparents' inheritance. So I think the cost of it is a problem. It's just not feasible. So unless it is state funded, unless the government or health benefits pay for it, it isn't useful to us." A Port Colbourne woman shares the same concern: "There are a lot of us who don't have a lot of money, and I found I couldn't afford a lot of support things. But it's great where we can go to something social that we don't have to pay for."

Most women we interviewed stressed that formal support programs were vital to their ability to live with breast cancer, but the informal support they received from family and friends was also valuable. Unfortunately, for the four Aboriginal women in our study this was the only form of support available to them. Each woman described in distressing detail their lack of access to cancer information, resources, and formal support:

The doctor never said anything to me to do anything, and there was no group that I was informed to go to. I just had the support of my family and friends. That helped me. I only called the Canadian Cancer Society because a friend referred me to it.

The services just weren't there. I didn't have home support. They sent me home just after my operation. And there was no support. If it hadn't been for the Native Centre in my community, which would come and visit me, I don't know what I'd do. But there aren't a whole lot of support services out there [on the reserve].

I have a lady that was very supportive. She belongs to the national Native cancer thing on the New York side. I would talk to her and she got me to the first cancer relay ride. I really enjoyed that...She was a support to me, brought me books and a pillow for my arm. So it was with my own people that I got support.

I didn't get much support either after my operation. It's only the nurses that came down to change my dressings at home...My cousin would take me to the Native Centre. She's the only one that I had support from. Not the doctor, that's for sure, after he cut me open.

When we asked what formal support initiatives would be most useful to them, they mentioned opportunities to speak with other women living with breast cancer and basic medical follow-ups after surgery:

I would like a support group. This [interview] isn't a support group, but what we have here now is good. You know, it's good talking amongst each other of our

own people, even with non-Natives who've battled with cancer. When you're first diagnosed with it, you don't know what to think. You think the worst, and you try not to think the worst. I don't remember seeing any information at the clinic. Maybe there is. I want to go back there to see if I overlooked anything. I just found a pamphlet on all the stats, but I don't recall seeing any support group or breast cancer society. I didn't see any of that.

I went online to read other ladies' stories, and that was a comfort because they had already been through it. So there's like hope at the end of the rainbow, so that was good.

“You don't know what to do with the pain... There's just no resources there [on the reserve]... I didn't have no nurse come to check on me. I didn't have anybody. That hurt, because that's what caused me to feel really, really alone... You don't know what to do. So a medical nurse should go to each person, sit across from them and ask if they have any support... The hardest part of having breast cancer is that you sit there for six weeks before you get a diagnosis. That's a long time, and the hardest part for a human being is the waiting and not knowing. And there's no support at that time when you're confined to your home.”

When I got home [after surgery] it hurt and I felt the pain a lot, of course, and I wanted somebody there to hold my hand while I talked about stuff like this. It would be nice if you came out of the hospital and you have somebody there to talk to while you're in pain and about what happened to you... I would like to have somebody there to talk to, somebody to tell you at least that you don't need to feel ashamed or guilty, and that they're there for you.

These quotations reinforce other participants' view that formal community-based support programming is an invaluable part of women's struggle to live with breast cancer. But if 'traditional support groups' and costly programs offered far away from home are not women's first choice of support, what benefits do they think they could get from community-based expressive arts programs based on practices that are already a meaningful part of their everyday lives?

### C. The Potential Benefits of Expressive Arts

When we asked research participants to think about the connection between the problems they encountered with existing support programs for women living with breast cancer and their experiences with expressive arts in their daily lives, they discussed at great length the personal benefits they got from the arts, benefits they think are a vital aspect of learning to live with breast cancer. By emphasising that these benefits are an essential part of their lives, participants implicitly - and at times explicitly - suggest that expressive arts can be excellent therapeutic tools. Women claimed they would actively seek out these activities, if they were available. I discuss this in more detail in the last section of this report.



Our participants discussed 9 main benefits they enjoyed from expressive arts that enabled them to live more comfortably with breast cancer. Many of these categories of ‘benefit’ overlap, although they are analytically separable. I list each below, followed by a selection of supporting quotations that contextualise these benefits and suggest how they could contribute to improved community-based support programming.

### 1. Expressive arts relieve stress

I really enjoy painting, especially landscapes. I think back to my childhood and I paint Bluebell Woods and things like that. It really helps when I’m really stressed, to go to my blue room and do some painting. I just so enjoy representing the scenery, and the sea, the ducks and birds. I just love doing that. It’s really healing.

You have to [create things] or you will end up feeling sorry for yourself and drive yourself crazy. It stops you from thinking about death. It doesn’t matter who you are, if you go through something like this you will think about death. So, you have to keep your mind busy. You start crying for nothing, and you feel sorry for yourself. But creating helps you feel better.

I really enjoy [making stained glass]. I find it very soothing and beautiful.

When I was first diagnosed I got into knitting, and that was extremely soothing, because it just diverted my attention and I had to focus and I created a really beautiful piece. It’s soothing, as well as stimulating.

I bike out in the country where I am alone with my own thoughts. I need to be able to appreciate the nature that surrounds me... That calms me. I can come back to that beautiful picture in my mind and so my stress level goes down.

### 2. Expressive arts emphasise the beauty in life

You need to see beauty everywhere. I started my chemo in January, but I’d still drag my butt out for a walk... I needed to be outside where there was something beautiful in life. I had to look at something that was perfect.

I’ve done quite a lot of writing, and that’s very cathartic because it helps you to work things out. Reading is connected to writing. And I think that writing and reading are almost acceptance. Through reading and writing, as well as other arts, visual arts, you just contemplate on things of *beauty*, and when you do that for a long time things come to you that you can write. A lot of the reading was very helpful to me, archetypal and mythological stuff... The biggest thing I got out of that archetypal kind of reading is that cancer isn’t really something that you really need to fear, but something that we need to nurture as part of the wholeness of our bodies... We have to prepare ourselves through these wonderful things like Reiki and chanting and getting into nature. The beauty of nature really does it on all levels. That connection is missing in regular medical therapy.

When I was out walking I found the most beautiful spot in Fort Erie. You can collect rocks, you can collect shells. As Native women, our role with water is key, it's our responsibility to look after the water... Going to the water, listening to the drum, all those things are very healing. Like sharing like this. I think that a lot of that expressive stuff should be incorporated into breast cancer support. You need connections to people and beauty.

### 3. Expressive arts connect women to life

I find that art is totally engrossing. I start drawing and it really moves my thoughts totally away. It's not that art is going to make you better. But once you get drawing and analysing, the process brings you peace, because it brings you to the present moment, not projecting to the past and future. And there are very few things in our lives that help us be fully alive, present and connected.

This probably sounds corny, but I can *feel* connectedness, *that's* what it is with the arts. Maybe it's about making us look at things differently... Maybe it's being a little bit more calm, less anal, slowing down.

We need connection through art, the connectedness to the being here and now.

When I was young I was an Indian dancer, on the reserve. I danced and sang. That was nice, I really enjoyed it... So I hope they have a PowWow soon at the Native Centre. I enjoy watching those people dress and singing. It takes me back to my youth when I was on the reserve.

When you get into a sharing circle and share with people that have the mindset, the stories just come. Just like sitting here, sharing stories about dancing, even if it wasn't anything related to the breast. It brings out good memories about life, things that make you laugh and feel happy. Those kinds of stories, those are the things that are healing... So that space and time that you're sharing, you're healing too because you're laughing. Everyone is understanding because you're all sharing it at the same time. I see sharing circles as a form of story telling. It just comes out natural and right.

I do a lot of imagery, and it helps me... It helps the flow of energy and connects what's closest to my heart... I need my life connected, because if it isn't I cannot continue this journey. It makes me very, very strong, gives me a lot of courage. It's about my inner self.

I'm just lucky that I'm in tune with nature. I'd rather do that, which is free, than spend a lot of money. I look for nature trails or conservation areas, and I do imagery when I find a good spot. For 20 minutes I connect myself with everything around me, and my heart is at peace with who I am. I should be thankful that I'm still here.

#### 4. Expressive arts are relaxing

I like to work with my hands, like when I do my quilts. I made over 50 and I want to make more. It is a good therapy. It's relaxing. I think of nothing else, and it keeps your hands and mind busy.

Knitting and running are calming, but you also get something in the end, create something tangible. You get a high.

I am sure that painting would help many women, because with different colours you can say a lot, express yourself. No matter how you use colours, combine them, you can express yourself. It helps you unwind, relax, and it keeps you busy, keeps your mind busy.

#### 5. Expressive arts enable women to express their experiences with breast cancer

I found the journaling to be very therapeutic. I'm not normally a writer, but I get inspiration and write down my thoughts and feelings and experiences basically for me and my family. So, that's therapeutic, it *frees* me... Since doing that I don't fear death, because I looked it right in the eye and knew I would be OK... Dealing with the issue and writing is what has freed me from the fear I feel. Putting it down on paper was really good for me.

I think that art therapy is good... It gives an expression for people who don't want to talk about things. It helps them know how to change things. It's pretty good, art therapy.

In your regular daily life, after you have surgery, that's an expressive art in itself. Just that you *exist* in what you do, how you learn to carry yourself and get to know your new body.

#### 6. Expressive arts build mental and physical strength

In terms of art therapy, dancing and moving your sick body gives you the strength to live life.

I can also definitely relate to exercise, because I have noticed that everything changes for me. My whole emotional landscape changes. As long as my body is moving I'm good.

I'm totally enchanted [by chanting]. It's wonderful. It touches me internally. But then there were already 10 other people who are vying for the next session, so I may not ever get in again.

I want to do everything in my power to make sure I stay healthy, including appreciating nature and listening to music and singing at the top of my lungs in the shower. That's for *me*. And that's where my strength comes from, from inside.

I write journals. That's the one way that I keep myself sane.

#### 7. Expressive arts transport women to another time and place

The chant is so powerful. It's got to be an art because it resonates in your body. It speaks to your cells. It's amazing. It transports you to another place.

When I play the piano I lose myself, and that helps.

You need something to take your mind off yourself, and arts and movement are helpful just to take your mind off yourself. Break that going around in circles. And sometimes that involves reaching out to others, but also getting a new perspective using creativity, whatever form that takes.

I found that knitting was just so soothing and just took me away from my problems, because I was totally focussed on something else, creating, and that's what interested me in coming to this interview.

With knitting you see progression. You see the challenge, and I need to be challenged. I need to be completely focussed on something other than a dilemma...Reading too is calming and satisfying, something to completely alienate yourself from the present of what you have to deal with.

#### 8. Expressive arts help women stay positive

Breast cancer is a lifelong thing you can't just cure. You can't think, 'Oh, I'm going to get well.' It's your whole life. You have to change your way of living. Be positive and do that using meditation, creation, and relaxation. I found I feel much better since I've been thinking positively.

I stopped playing the piano and painting. But it's just now, after I realised that I need to make sure of myself creatively, that I've gotten back to art and writing too.

Arts build up your confidence, to say another encouraging word to another person that can bring joy and comfort for you too. They keep our morale up so you're not feeling so down. They help you to get out of yourself. All these things are the benefits of art activities.

I think out of therapeutic art things you might find gifts you never knew you had, because you never really explored it.

If you feel ill, you are ill. But you can do something that makes you feel good about yourself. You have accomplished this by making a pie or doing a watercolour painting. I think it makes you feel different, better about yourself.

#### 9. Expressive arts make women feel productive

I guess in a sense you're accomplishing something with art. It gives me a sense of belonging and purpose.

I got involved in recycling cards, making new cards out of old cards, which is fun, creative, and takes little brain power...It's been fun and rewarding. I like things that are fun, and I feel good about *doing*.

You get a sense of satisfaction of *doing* something. I've created this with my own hands, no matter how well it turned out. That process, to me, is like meditating, because you're so involved you forget about mundane things. I can feel good about myself, and the big breast cancer isn't staring me in the face quite so much. So, it's about self-worth basically, for me, in doing things like that.

In summary, participants suggest that expressive arts have great potential as therapeutic tools related to breast cancer support because of the multiple and significant benefits art activities provide. They also claim that 'art therapy' needs to be done routinely to feel its deep effects, and that the *process* of making or doing art in the here and now is far more important than the products themselves.

#### D. Visions for Future Expressive Arts Support Programming

After having thought through the benefits of expressive arts, we asked participants near the end of each focus group discussion to consider what types of community-based art support programming they would like to access, when, where, and how. They mentioned writing and story-telling workshops: "Workshops on how to better express yourself would be helpful. Writing is something that anyone can do, to help you write down your thoughts." Attending, as well as participating in theatrical and musical performances was another suggestion: "What about a place with music to listen to or some instruments, or where someone would deliver a bit of a performance, a dance or skit or if we were able to watch someone paint or share that visual kind of thing. Images are very therapeutic. You lose yourself a little bit in them, get away from it all."

Most participants seemed to prefer group-based activities that allow them the opportunity to connect with other women in a positive, creative social environment that "shows people there is a life after breast cancer." For example, a woman in Port Colbourne thinks "We need to express ourselves in a group, and we can do it because we are concerned about each other. But it's important to have a good time too. You come away happier than when you went in." Another woman agrees: "I think it's important to get into constructive groups like this...somebody will likely teach you to knit something or sculpt something. And so you're learning from each other.

You connect.” Whether the expressive art form is listening to music or working with clay or journaling, women stressed, as we can see in the previous quotation, that an educational focus is also important, that new opportunities for learning are a vital part of recovery.

In terms of when women would like to have expressive arts programming available to them, most participants stressed “sooner rather than later,” preferably within the first six weeks after diagnosis when women are trying to come to terms with their diagnosis and treatment options. As an Aboriginal participant emphasises,

The support needs to be there right from the beginning. Someone to say, ‘Do you have any questions?’ ‘What does this mean? What does asymmetrical density mean?’ ...What I hear from everyone here is that they felt alone, the anger, the hurt. You feel brushed aside, just a number. That was what I felt when I was waiting for my x-ray. My humanness didn’t matter, the fact that I was upset didn’t matter, no one could give me an answer. So, right from the beginning, which is frustrating, there needs to be support and the opportunity to express your feelings and experiences.

Some participants would have found arts interventions useful even *during* their treatments: “You know, we all sit there for just *hours*, having our chemo...It would be great to do something creative and constructive with that time. For example, someone to teach you how to knit. Someone to teach you how to paint...I’d *love* it if I could do that. I’m just sitting there with an IV in my arm, so why can’t someone help me create and express myself. And we’ve already got the place!” One woman had such an experience. She told us that “After surgery I needed 16 weeks of treatment...I took treatments every day from May to July, coming home every weekend...[The atmosphere] was very supportive and nice. Three times a week there would be entertainment and arts to lift our spirits. I found that very relaxing and soothing.” These insights demonstrate that while expressive arts support programming is welcome at every stage of post-diagnosis, it can be especially useful early on in the process.

Participants were equally committed to having support programming available in their local communities, preferably at a dedicated “friendship centre” or “satellite station” (rather than disparate and ever-shifting locations) that provided a communal, positive, creative, and energetic social atmosphere: “I’d like to see action, I want to see things happening, instead of people just talking and eating...If they’re implementing things at a centre in Fort Erie or St. Catharines, then why not here in Six Nations as well?” Many women also discussed the timing of these events; a mixture of afternoon and evening, as well as weekday and weekend activities would provide the flexibility women need to fit arts programming into their treatment schedules and daily routines, as well as the hours of the day when their physical energy is at its peak.

Finally, while most participants have been proactive in their search for community-based breast cancer support programming, many of our participants, including the Aboriginal women, wished the programming, or at least the information about programs, had come to them. They envisioned a ‘welcome wagon’ of sorts, people who would contact them once they had been diagnosed to inform them about what programming is available (and when and where), and to actively encourage them to participate. Participants stressed that it was important to have that personal contact, as well as a good description of the programs that made them sound attractive, so they know that they “aren’t alone in the struggle” and that they have a place “where you can

have tea and company, some good conversation and creativity. I always feel better about myself with that. It's always the good company, which is uplifting and fun. It's *good*."

In summary, these four focus group interviews with 31 women from the Niagara Region who are living with breast cancer provide rich insights into their support needs and preferences, their previous experiences with expressive arts, the benefits they receive from participating in expressive arts activities, and the types of expressive arts programs they would like to access and how. On the whole, our research participants already have fairly well-developed experiences with expressive arts in their daily lives, as well as understandings of their benefits that could be formalised for the benefit of more women and developed in a way that women can make use of them even more fully and systematically in their healing journeys. These activities are useful in dealing with the trauma of diagnosis and treatment, as well as recovery, and therefore have the potential to be an excellent supplement to existing community-based breast cancer support programming in the Niagara Region.