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PAPER

Cycles of silence: First Nations women overcoming social and historical barriers in supportive cancer care

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Abstract

Background First Nations people with cancer in Canada confront several critical inequities in physical and psychosocial domains. First Nations women are at a particular disadvantage as they are disproportionately affected by social determinants of health, but how they navigate these challenges within their communities is poorly understood.

Objective Our study explores survivorship experiences of First Nations women with cancer and their caregivers. Drawing from a larger data set on survivorship, we identify several major barriers to cancer communication and support in First Nations communities.

Methods Our team conducted a participatory, arts-based study using several data collection methods (interviews, sharing sessions, photovoice, and other creative activities) with 43 participants (24 cancer survivors and 19 caregivers) from four First Nations communities in Canada.

Results Two major themes have emerged out of our data analyses: (1) suffering without support leads to cycles of silence and (2) community-based supports can disrupt these cycles. We identified several social, historical, and institutional barriers to speaking about cancer and finding/providing support; however, communities met the challenge of silence through voluntary and unsolicited provision of support.

Conclusions Widespread silence around cancer reflects both the limited access First Nations people have to formal, supportive programs and services, as well as the creative ways they provide emotional, social, and financial support within their informal networks. Beyond the support of their communities, they also required institutional provision of care that is culturally safe, addressing the colonial impacts on cancer communication and the disproportionate burdens of disease in First Nations communities.

KEYWORDS

cancer, communication, First Nations, oncology, supportive care, survivorship

1 | BACKGROUND

Over the last several decades, First Nations, Inuit, and Métis populations in Canada have witnessed increased cancer incidence and mortality rates compared to the non-Indigenous population.[1,2] Inequities across many domains—from survival to quality of life—loom large over Canada's Indigenous peoples.[1] For instance, during treatment, First Nations and Métis patients face significantly higher distress scores for pain, depression, anxiety, and shortness of breath than Caucasian patients.[3] Rural First Nations cancer survivors show significantly higher levels of anxiety and higher unmet needs in all categories of an unmet needs survey than non–First Nations rural survivors.[4] These differences may be attributed somewhat to widespread perceptions and beliefs within First Nations communities that cancer is a death sentence.[5,6] Fear of cancer often results in silence and isolation, which may have an impact on accessing care and communicating about health needs.

Cancer care research and programming have not met the distinct circumstances and needs of First Nations, Inuit, and Métis peoples in Canada.[7–9] Support across the cancer-care continuum is lacking in many communities in Canada; a recent national survey found that less than 50% of First Nations communities has local cancer programs or services and none have formal palliative care programs.[6] Gaps in care are not limited to Canada. A systematic review of American studies found that many Native Americans endure stigmatization, isolation, and poor quality of life in part because they do not have access to culturally relevant care services that recognize the importance of spirituality, local conceptualizations of disease, and family/community participation.[10] Across the globe, common barriers to cancer treatment among Indigenous populations include cultural insensitivities; socioeconomic disadvantages; mistrust of mainstream health systems founded upon historical and ongoing marginalization; and complexities associated with healthcare systems, procedures, and services.[4,11–14]

Barriers to supportive cancer care systems require particular attention. Colonial legacies of extermination and assimilation of Indigenous peoples have played a significant part; for example, traumatic memories of residential schools continue to mediate First peoples' relationships to governmental (including health) institutions.[5,15–18] Communication within healthcare settings is stifled by institutional environments where racism, invisibility of cultural differences (eg, in communication styles), and unearned expectations of trust persist.[14,19] Communication with Indigenous peoples may also be inhibited by inaccessible medical jargon, stereotypical evaluations of patients' life circumstances, racialized clinical judgments about their health needs, and displays of impatience with people seen as troublesome.[14,20] Many Canadian healthcare practices and policies with First Nations patients lack cultural safety perspectives that highlight sociohistorical determinants of Indigenous health (eg, colonization, displacement, and racism) and examine power differences between clinicians and their patients.[15,21] These systemic barriers have led many First Nations, Inuit, and Métis peoples to fear and avoid medical consultation until their health has severely deteriorated.[13,15,16]

Emerging cancer research has identified that physical and psychosocial health outcomes are mediated by intersecting factors of ethnicity, marginalization, and gender inequality.[22–24] Indigenous women endure a disproportionate burden of illness in relation to Indigenous and non-Indigenous men, possibly as a result of intersecting modes of marginalization.[16,25,26]

Our research team is involved in a program of research involving Indigenous peoples affected by cancer. The program was initiated by a pilot study on First Nations and Métis experiences with breast cancer, which found that many women feel they have “fallen through the cracks” of cancer care.[9,27,28] More research is needed on how women experience and combat these inequities.

Our *National Picture* project explores the cancer survivorship experiences of First Nations women within the context of inequitable health care and intersecting factors affecting women's physical, mental, social, and spiritual well-being. The theoretical orientation of the project is informed by a postcolonial perspective that “draws attention to power and to the historical, social, economic, and political relationships and processes” that Indigenous women confront.[29] In particular, the struggles of First Nations women affected by cancer—whether as cancer survivors or caregivers—are situated as sequelae of social and historical discrimination within institutional policies and practices.[25] Analyses move toward identifying First Nations tactics and strengths that help to overcome these products of colonization and racism. This project is funded by a Quality of Life grant from the Canadian Cancer Society Research Institute. Ethics approval for the study was issued by the University of Ottawa Research Ethics Board, as well as several local research councils based within the First Nations communities that have participated.

2 | METHODOLOGY

The broad research goal of this arts-based, qualitative project is to develop and disseminate knowledge of First Nations women's experiences with cancer survivorship, either as a cancer survivor, a professional caregiver to someone with cancer (eg, nurse), or informal (family) caregiver. Some of the dominant themes of the project include Indigenous perspectives on healing from cancer (eg, spirituality and traditional medicines), sources of community support, and structural barriers to accessing cancer care. Within this manuscript, we focus on findings regarding the processes and significance of silence around cancer.

Elsewhere, we have outlined our research protocol in detail.[30] Briefly, our methodology draws upon participatory research paradigms together with arts-based methods, both of which prioritize participants' knowledge with the aim of effecting transformational objectives in policy and practice. Participatory research methods have been shown to foster community engagement and empowerment among Indigenous populations,[31–33] making them a suitable fit with postcolonial research that aims to identify Indigenous resilience against contemporary forms of oppression. Arts-based research has been widely used with marginalized populations, especially photovoice, a methodology that captures participants' experiences and needs visually.[34,35]

2.1 | Sample

To date, our project includes 58 participants (27 cancer survivors and 31 caregivers)[2] across 4 communities in the provinces of British Columbia, Ontario, and Quebec (Table 1). Most survivors have breast cancer (75%). The remaining 25% have colon, kidney, or skin cancer, or Non-Hodgkin Lymphoma. The project is in its final year and, as of this writing, a fifth community in Quebec has recently joined. We begin by working with local “community champions” who liaise with community members and authorities to determine if the project is of local interest and given permission to proceed.

2.2 | Data collection

Once we have permission, data collection occurs over 4 phases: (1) an initial sharing session, (2) arts-based activities, (3) follow-up interviews, and (4) a second sharing session. The initial sharing session includes cancer survivors and their caregivers, who are invited to share their stories and to talk about their major challenges, sources of support, and understandings of healing. Secondly, only survivors are invited to engage in optional arts-based activities to reflect on and facilitate their storytelling[3]; in particular, they are given cameras (if needed) and journals and invited to use them to communicate any significant aspect of their experiences with cancer. They are also offered follow-up

TABLE 1 Participant and research site details

Community	N	Survivors	Caregivers	Age Range	Age Mean
1	11	4	7	50-73	61
2	9	7	2	43-69	56
3	7	4	3	44-63	49
4	31	12	19	27-81	61

individual interviews to discuss the content of their photographs and journals, including questions about the meaning and process of engaging in creative activities. In the final phase, all participants (survivors and caregivers) come together in a second sharing session to discuss the main messaging or themes of people's stories and who should be targeted for dissemination of the project findings. All interview and sharing session data were audio-recorded and transcribed. We report primarily on verbally generated data, along with selected photographs.[4]

2.3 | Data analysis

Data analysis also occurs over several phases. Participants start the analytic process insofar as they are asked in the interviews to talk about the meanings of their photos and journal writings and how participants might relate them to broader themes (eg, support, personal strengths, healing, culture, spirituality, etc). In other words, we ask participants to interpret and thematize their own data, as is typical in a community-based research project. Their analyses are recorded as part of the interviews.

All data (photos, journals, and transcripts) are then uploaded into NVivo 10, where it is further analyzed by 2 team members (CH and RT) using standard qualitative techniques (line-by-line coding, cross-case comparisons, and hierarchical arrangement of themes based on presence in the data) to produce an integrated list of themes and subthemes. NVivo enables users to code data directly into themes or "nodes" and construct a hierarchy of superordinate and subordinate nodes; our analyses produced the following 5 nodes: life impacts of cancer, cancer care systems, systemic challenges (eg, discrimination, inequities, and barriers), (concepts and processes of) healing, and sources of support. Participants' and team members' analyses are often synthesized to become overarching categories; for instance, the cycle of silence we articulate here was formulated by CH, but most of its components (eg, historical loss and lack of support) were identified by participants as dominant themes in their personal and communal narratives of cancer.

We have completed analysis of 4 communities and distributed a detailed summary of the above nodes, including theme definitions, their relative presence in the data set, and sample participant quotations and photographs to the remaining research team members. The team reviewed the organization of themes and examples for fidelity, coherence, and representation—this last criterion, under the rubric of participatory research, ensures that participants' own perspectives have been respected and included in the analytic categories. We have also taken the summary to community champions and select participants (3-4 per site) who expressed interest in contributing to the process to review and confirm the path of our analyses, which they approved without revision. Through this process, the research team and consulted community members agreed that communication and access to support were 2 priority issues.

3 | RESULTS

A first major theme in participants' data conveys a dominant psychosocial challenge for participants: that *suffering without support leads to cycles of silence*. Two subthemes create and maintain this cycle: (1) historical origins of silence and (2) current limitations in access to support. The second theme demonstrates that *community-based supports can disrupt these cycles* through a variety of creative strategies. The 2 most common strategies were (1) creating safe spaces to talk and (2) supporting without speaking. Below we describe these cycles of silence and strategies for disrupting them.

3.1 | Suffering without support leads to cycles of silence

3.1.1 | Historical origins of silence

Participants from all 4 communities discussed cancer as a hidden disease with new diagnoses sometimes concealed from family and friends. Cancer survivors described their community's reaction to their diagnosis as an assurance of death. For example, Clarissa reported that some of her family members thought she was dying when she was diagnosed with non-Hodgkin lymphoma:

> *People hear that you have cancer and they automatically think, "Oh geez, you know 6 months, 9 months." They don't really sit and talk to you. They don't really get to know about what the disease is really doing and it's really hard to explain that to your siblings and what's going on with you.*

Clarissa said her brother in particular felt helpless and overwhelmed: "He's sort of my big brother, big protector. So he sort of feels that, 'I can't protect her on this.'" This fatalistic sentiment made it difficult for women with cancer to speak openly with family members (including caregivers) about their needs and concerns.

Furthermore, cancer survivors acknowledged the many people they knew to have died from cancer. Almost every survivorship story also contained a bereavement story, as Perrine illustrated at the beginning of her narrative:

> *There were 5 of us that were diagnosed at the same time. One was my Uncle Dean, the other was my cousin David, and they both had prostate cancer. My cousin Edna had it and my cousin Penny, they both had breast cancer. I had colon cancer. We were all told at the same time…We survived, Edna, Penny, [but] my uncle and my cousin [David] died.*

Beyond this legacy of grief, participants provided a second historical source to cycles of silence, related to colonization of their communities. For instance, residential schools had a major impact on how survivors and caregivers communicated with each other. Chantal, a bereaved caregiver to her mother, talked about the legacy of the schools and how they influenced her family's interactions when her mother experienced throat cancer:

> *I don't talk to my sisters anymore because we come from an Ojibway family that was really ruined by the residential schools. The dynamic that was taught at the schools was, "Keep secrets, don't tell the truth," because the truth might hurt someone or you might hurt yourself and get into trouble…Communication would have solved a lot of problems but the dynamic in residential schools was, "Don't communicate, keep everything secret," and then the families perpetuate that rotten dynamic and that's exactly what we got to and I've just had to leave my family behind.*

Expressing similar experiences, some participants started their cancer narratives with stories of being taken away to residential schools, which served as a preface to help listeners understand how difficult institutional experiences may have influenced later experiences of health care.

The 2 major reasons for silence—fears and cumulative grief of losing loved ones to cancer and enduring legacies of colonial abuse—suggest that First Nations women may require cancer support that recognizes historical losses and oppressions within their families. The following section demonstrates that ongoing inequities perpetuate these historical experiences of suffering and loss.

3.1.2 | Limited access to support today

The silence surrounding cancer was complicated by the highly visible effects of cancer (eg, hair loss) and the challenges associated with accessing treatment and supportive care within or close to the community. While survivors valued the support of loved ones, they knew that very few resources were available to them and their caregivers during hard times. Survivors and caregivers alike looked to institutions for respite—in particular, financial aid for expensive medical travels, emotional and spiritual counseling for distress, and caregiver support for exhausted families.

One major limitation for survivors was feeling disconnected from healthcare and supportive professionals who were not locally based. Karen said she sought out resources for recovering from mastectomy surgery and found there was nothing and no one she could reach:

> *I tried to find people here, I called the numbers they gave me at the hospital when I got back. I couldn't get any results with that. Nobody ever came to see me or anything. So I more or less just did everything on my own.*

Participants also indicated that their community clinics lacked proper funds to provide sufficient care and support for cancer survivors. Cancer care had to be accessed outside of the community, in a nearby urban center, and travelling for treatment was costly. For example, Perrine said her community's health council provided $46 per week to pay for travel to appointments she made twice a week to the nearest hospital an hour away. The funds were inadequate to cover her expenses, so she started selling personal items to help pay for her travel: "It was tough to have not enough money for travel or food. I managed because I wanted to get better…This needs to improve." Perrine's words reflect the financial challenges faced by many First Nations women, who are already contending with poverty, as well as the pittance they received to make their appointments.

The reported barriers to institutional support extended beyond geography and economics. In urban settings with more resources, participants criticized the lack of respectful care for First Nations patients. Both survivors and caregivers stated they had received differential treatment, which perpetuated their silence and limited their access to care. For example, to some, support groups seemed uninviting and spaces where "white women could only go" (Pamela, survivor of breast cancer). Although relationships with health care professionals varied, it was generally recognized that First Nations peoples do not have equitable access to care. Sharon, who cared for her child with leukemia, talked about being denied financial aid, including welfare for having to leave work to be her child's caregiver:

> *[My family were] the ones who came up with the money for our rent because we did spend a lot of money driving when [the health authority] cut us off…My husband and I, we both worked all our lives for what we have, we lost it overnight. But we were treated differently.*

After hearing Sharon's story, Frances, an Elder who worked as a professional caregiver in a hospital, commented on the major disconnect between the reality of healthcare for First Nations peoples and broader public perceptions that they receive preferential care by the federal government: "[People are] always calling us out, [saying] we're well taken care of, we get everything for nothing. Well, now you hear what we got." When asked how to address the struggles of First Nations affected by cancer, her pithy response was a challenge to fix institutional barriers: "Correct the higher level, that's all we ask for."

In summary, participants discussed several systemic and historical barriers to accessing cancer support, which maintained their silence and marginalization. In the following section, we discuss strategies participants used to overcome these cycles of silence.

3.2 | Community-based supports can disrupt cycles of silence

3.2.1 | Creating safe spaces to talk

Along with discussions of systemic challenges, participants shared stories and photographs exemplifying their resilience. Survivors stated that sharing their stories in community settings (including the project's sharing sessions) was a way to address the silence that can surround cancer. Josie said a local cancer fundraiser provided an opportunity for her to voice her breast cancer experiences (Figure 1):

> *I was going last year to the Relay for Life and I didn't go for some reason. And then this June I said, "I'm going." I think it's the first time I finally told everybody and anybody that I was a survivor. And we did that little walk and this and that, talked to other people. And you know, there's a lot of people I know that didn't know I had cancer, I mean that's when I first really decided to let people know.*

FIGURE 1 Josie holds up a shirt from the Relay for Life fundraiser, where she shared her story of cancer for the first time

The cancer survivors within our study talked about sharing their stories for the first time as a rite of passage—a ceremony or induction that "outed" them to their communities. Pamela explained that she told her story publicly to show what breast cancer treatment was like (Figure 2):

> *I realized that I wanted to help anybody that was going through that…It was the unknown that was really terrifying for me. I didn't know how I was gonna react to the chemo…I posted it all on Facebook for that reason, for people to see.*

FIGURE 2 Pamela had her son take this photo just before her radiation treatment, which she then posted on her Facebook page to show others what it was like

Pamela's story reflects a desire among survivors to be voices of hope for their communities and to care for others after being cared for. Survivors said they were not typically asked to share their experiences, so they took the initiative in trying to create safe spaces for talking about cancer within their communities.

3.2.2 | Supporting without speaking

Participants suggested that communication is often indirect and nonverbal when someone in the community is ill. It was seen as important not to treat silence as a barrier in itself but to understand its various roots and effects. For example, the challenge of being able to speak was sometimes reframed as a call for caregivers to learn how to hear and understand what is expressed in silence. Chantal said that good caregivers know how to help without needing to be asked:

> *The Elders might not say anything to you but you know what they're thinking by their gestures, by their body language, by the way they move their eyes and stuff. That might be a hard language for anyone to learn but we have to learn to look beyond what the person says, what the patient is saying, you have to look at what they're not saying.*

There is space for truth-telling as well, but it depends upon the context. It must be the right person speaking and the right time to talk, as Chantal explained:

> *Sometimes you just need to get the message from the right person too. An Elder told me, "Pull yourself together. Your mother doesn't want to see you being a mess like this." And then, within two days I'd stopped my crying, I'd stood up straight, I took a shower. I hadn't showered in five days. And then I just got on with the business of helping my mom get through treatment.*

In this light, communication between survivors and caregivers appears to be a nuanced subject; participants did not always see silence as a barrier or straight talk as the proper course.

In addition, participants talked about how, in lieu of a space to talk about fears, caregivers provided mostly nonverbal forms of support. Clarissa, for instance, received a handkerchief from her sister after she lost her long hair. This gift gave her strength to be seen without hair (Figure 3):

> *I wore it everywhere and every time I put it on I think it gave me more and more strength. I didn't care what I looked like, I didn't care that I lost my eyebrows, and it was just a matter of putting that handkerchief on saying, "Okay, you're going back out into the community today," and I did. Not once did I shy away from anybody.*

Giving donations at fundraising events was perhaps the most common nonverbal support identified across the 4 communities, although it was not always easy. Konwahentawi had painful memories of people first refusing to help her raise money for complementary breast cancer therapies: "Some of them weren't even looking at me. I felt so shitty, I felt like a bum, like I was asking for a handout." Her family then

FIGURE 3 Clarissa wears her handkerchief while at the cancer centre

stepped in to help her run several successful fundraisers. Even then, Konwahentawi stated that it was also hard accepting help (Figure 4):

> *It's hard to ask for help like that when you've never really done it before. And for people you don't even know to come out of nowhere and help you, the challenge is putting your pride aside and just letting people. Letting your guard down and letting people help you.*

Thus, survivors and caregivers found creative ways to support one another despite structural challenges, which made it possible to speak about cancer and/or to be caring in other ways when speaking was difficult or inappropriate.

4 | DISCUSSION

Through participatory, arts-based methods, our research has explored the postcolonial experiences of First Nations cancer survivors and caregivers, placing their psychosocial struggles within cycles of silence maintained by systemic inequities.

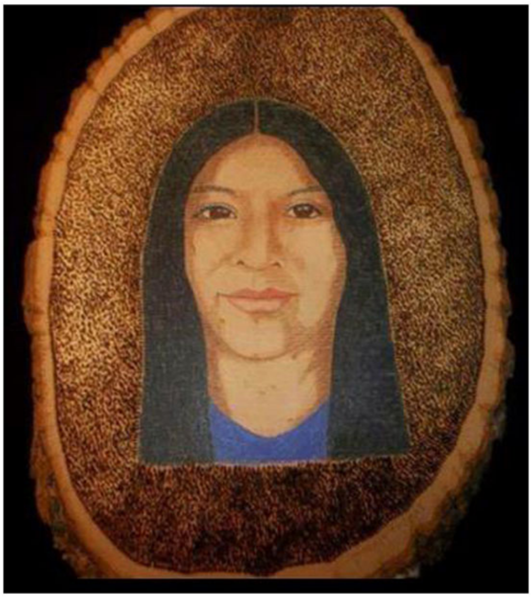

FIGURE 4 A local artist created this portrait of Konwahentawi and donated it to one of her silent auctions. Konwahentawi kept it as a reminder of the generosity of her community

We found that Indigenous peoples' silence around cancer is much more complex than has been typically conveyed in research. Their silence is often situated as a "cultural barrier" within global health research literature, that is, a static communicative style characteristic of Indigenous cultures. Delayed diagnoses and poorer outcomes are attributed to limited knowledge and exaggerated suspicion toward the benefits of cancer prevention and screening.[5,36–38] By comparison, this study revealed several other sources that can perpetuate cycles of silence. Participants reported few opportunities to discuss their experiences with cancer, due in part to colonial histories of loss and oppression, as well as limited availability of institutional and/or informal supports. To conceptualize, this silence as a cultural trait alone risks overlooking the marginalization Indigenous peoples experience within healthcare systems, which is inseparable from broader histories of colonization.[17,25,39]

The cultural barrier narrative also suggests that Indigenous peoples' fears of cancer are largely unfounded and are not in keeping with advancements in cancer survival rates. On the contrary, perceptions of cancer's fatality are aligned with the typical cancer trajectory within First Nations communities in Canada, where inaccessibility and inadequacy of services across the cancer continuum lead to later stage diagnoses and more deaths.[6] Participants' stories about residential schools and differential treatment within clinics suggest that there are colonial foundations to their silence and fatalism that are still in operation. For example, the remoteness of many communities in Canada, which severely limits access to health care, education, and many other forms of social support,[4] stems directly from Canadian policies of land dispossession and displacement. Furthermore, Indigenous health continues to be impacted by ongoing neglect of federal responsibilities signed in treaties and land agreements, such as ensuring equitable access to healthcare, education, and housing.[40,41]

There is another, more positive aspect to the silence found in Indigenous communities. The power of nonverbal support and the ways in which silence speaks can challenge the idea that silence is necessarily a barrier. Participants provided many examples of individual and collective resourcefulness against the systemic challenges they faced, which reflect First Nations notions of resilience including subtle communication, community caregiving, and resistance to colonization.[42] Participants indicated that family caregiving was an essential part of their recovery and survivorship. These community-based practices of care need wider recognition.

Finally, despite evidence of community provision of supportive care, participants called for widespread reform in systems designed to alleviate the burdens of cancer. There is high demand among First Nations women for more culturally safe services that incorporate knowledge of social and historical factors shaping their experiences of cancer. Several valuable recommendations have been published for health professionals to develop culturally safe practices when working with First Nations, Inuit, and Métis patients, including more education on the intergenerational health and social impacts of colonization, critical reflection on harmful Indigenous stereotypes promoted in healthcare policy discourse, and patient advocacy work to ensure Indigenous peoples are able to access the services they need;[43] uptake of these recommendations could address colonial practices and inequities within health care systems and open culturally appropriate pathways to cancer communication and support.

5 | CONCLUSION

First Nations cancer survivors and caregivers report several sociohistorical sources to the prevalent silence around cancer in their communities, thus challenging dominant paradigms describing silence as a cultural barrier. Survivors and caregivers find creative ways to support each other and stay strong despite the many barriers they encounter; however, community resources can become severely strained if not complemented by improved access to supportive services and policy changes.

NOTES

[1] We use the term "Indigenous" when referring to international research that reports common experiences and effects of colonization across different geographical contexts (as recommended by Canada's Institute of Aboriginal Peoples' Health: http://www.cihr-irsc.gc.ca/e/48181.html#b). We use the more specific terms of "First Nations," "Inuit," and "Métis" when discussing Canadian contexts specifically.

[2] We must acknowledge the intersectional roles and complex identities of many of our participants. Many women involved in the study were also caregivers to others living with cancer. One participant identified as Métis and another 5 identified as non-Indigenous. They identified themselves as part of the communities studied (eg, as professional caregivers, spouses to community members, etc.) and were therefore included.

[3] Our initial research plan was to work with cancer survivors exclusively, but the communities we began working with requested that caregivers also be invited to the sharing sessions. In keeping with participatory methodologies, we amended the research protocol and objectives to include caregivers. However, the scope of our funding limited the extent to which we could collect individual data with caregivers; we will return to them in a future project, given their interest.

[4] Participants consented to the use of their real names and personal photographs on a data release form where they could choose their own level of anonymity.

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