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Barriers and facilitators to the engagement of physical activity among Black and African American cancer survivors during and after treatments

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Received: 24 October 2022 / Accepted: 18 January 2023 / Published online: 26 January 2023 © The Author(s), under exclusive licence to Springer-Verlag GmbH Germany, part of Springer Nature 2023

Abstract

Purpose To identify physical activity (PA) barriers and facilitators among Black and African American (Black/AA) cancer survivors that should be considered in future PA intervention development for this population.

Methods A community advisory board (CAB) of Black/AA cancer survivors and patient advocates guided in-depth qualitative interviews (n = 19) that were completed via telephone using a semi-structured interview guide. Interviews were transcribed verbatim, and data were analyzed using directed content analysis to detail a report of PA barriers and facilitators during and after cancer treatment. The CAB reviewed and interpreted these barriers and facilitators to identify the final results. **Results** Survivors (n = 19) of nine different types of cancer completed interviews. PA barriers during cancer treatments included physical and psychological suffering. PA barriers after cancer treatments included social and environmental constraints (e.g., lack of access needed for PA, safety concerns, and competing priorities). PA facilitators both during and after cancer treatments included family support, faith, and support from other survivors. PA facilitators during treatment also included feeling better after doing PA, setting realistic and flexible goals, and gaining a sense of control of one's health by striving for PA goals.

Conclusions To increase PA among Black/AA cancer survivors, PA interventions are needed that address structural barriers, include the role of faith, leverage family support, highlight the psychological benefits of PA, and use goal setting.

Keywords Cancer survivors · Physical activity · African Americans · Community advisory board · Barrier · Facilitator

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Introduction

Cancer remains a leading cause of death globally (approximately 1 out of 6 deaths) [1]. Black and African American (Black/AA) individuals are disproportionally diagnosed with cancer compared to individuals of other races [2, 3]. Black/AA cancer survivors also disproportionately experience treatment-related symptoms, side effects, and long-term effects [4–6]. Physical activity (PA) is widely recommended for cancer survivors to ameliorate many of these adverse effects [7]. However, most survivors do not engage in PA at recommended levels [8, 9]; furthermore, Black/AA survivors are less physically active than White survivors [10, 11]. To achieve health equity for Black/AA cancer survivors, focused efforts are needed to increase PA among this population.

Little research has focused on PA promotion for Black/ AA cancer survivors. PA barriers and facilitators have been identified among Black/AA survivors, mostly in breast cancer survivors and those who have completed cancer treatments. Known barriers include physical conditions (symptoms, comorbidities, fatigue, pain) [12-16], lack of accessible resources (facilities, equipment, environment, finances) [12–17], psychological issues (lack of interest, motivation, negative emotions) [12, 14, 16, 17], and competing priorities [12-14, 18]. Known facilitators include fear of cancer recurrence and comorbidities [16], PA-friendly environment [15], feeling better after doing PA [18], and leveraging church or faith for self-care and PA motivation [15, 16]. Few PA interventions are designed specifically for Black/AA cancer survivors [19]; of these, the majority have been tested among Black/AA breast cancer survivors who had completed treatment [20]. More PA interventions designed specifically for Black/AA cancer survivors are needed because research shows differences in predictors of PA between White and Black/AA cancer survivors [15, 21].

Given the paucity of PA intervention studies for Black/ AA cancer survivors, an enhanced understanding of how interventions should be tailored is needed across Black/AA survivors of multiple cancer types. Additionally, because it is recommended that people engage in PA from the time of diagnosis [22], identification of PA barriers and facilitators during treatment is needed. With this study, we aim to advance the knowledge of what influences Black/AA cancer survivors' engagement in PA during and after cancer treatments and identify the potential elements of a PA intervention that could meet the specific needs of this population. To achieve this goal, we examined personal experiences and perspectives about PA during and after cancer treatments through one-to-one in-depth interviews with Black/AA cancer survivors.

Methods

Subjects

This study was approved by the Institutional Review Board (IRB no. 19-3299) at the University of North Carolina at Chapel Hill. Participants were recruited through collaboration with a community advisory board (CAB) [23]. Two participants joined the CAB after completing the current study and then assisted with recruitment. Study information was distributed by CAB members, cancer support, and patient advocacy groups via social media and the UNC Hospitals Oncology Clinic. Eligibility criteria consisted of (1) being over age 18 at the time of the study, (2) self-identifying as Black/AA, (3) living beyond a cancer diagnosis, and (4) having access to a telephone. For clinic recruitment, a nurse

practitioner (TT) provided eligible patients with a study flyer with the study phone number. For community recruitment, flyers with study contact information were distributed or posted on social media. Potential participants expressed interest by calling the study team. They were then mailed an introduction letter and consent form. Eligibility confirmation and verbal informed consent were completed by telephone.

Data collection

In-depth semi-structured interviews were conducted via telephone between February and October 2021. Interviews were conducted by expert qualitative researchers with extensive experience facilitating similar conversations with Black/ AA cancer survivors (RT, JC, KG, AH, MYW). Each interview lasted approximately 45–60 min. The interviewers followed a semi-structured interview guide developed by the study team and designed to elicit participants' PA-related experiences and insights during and after cancer treatments. The interview guide was piloted with one participant who then gave suggestions to improve the final interview guide (Appendix). Participants received a \$50 Visa gift card for completing the interview.

Data analysis

Interviews were digitally recorded and transcribed. Transcripts were imported into Dedoose [24] for analysis. Directed content analysis [25] was applied to code transcripts using a codebook developed from the interview guide and notes taken during data collection. The codebook was independently applied by 5 expert qualitative analysts (RT, JCA, KG, AH, MYW) to several transcripts. The analysts then held iterative meetings to discuss and reconcile discrepancies and fine-tune codebook concept definitions and decision rules. Consecutive reconciliation meetings (4 totals) were held until consensus and replicability of coding application were achieved. After coding all manuscripts, analysts generated a report containing narrative summaries with themes, sub-themes, and illustrative quotes. Findings were organized to identify PA barriers and facilitators during and after cancer treatment. The principal investigator (RH) reviewed the report with the CAB (DFL, JLM, PD, KC) to make meaning of key findings.

Results

Study sample

Twenty participants consented, and 19 were interviewed; one did not participate due to scheduling difficulties. Participants were on average 56 years old (SD 12) and living past

 Table 1
 Demographic characteristics

Characteristics	Mean (SD)/ number (%)
Age	56 (12)
Gender	
Male	2 (10.5%)
Female	17 (89.5%)
Sex at birth	
Male	2 (10.5%)
Female	17 (89.5%)
Education	
High school, certificate, or some college	5 (27.8%)
Bachelor's	7 (38.9%)
Graduate school	6 (33.3%)
Employment	
Unemployed	2 (11.1%)
Retired or social security	6 (33.3%)
Employed	10 (55.6%)
Marital status	
Single	6 (33.3%)
Divorced	4 (22.2%)
Married	6 (33.3%)
Widowed	2 (11.1%)
Cancer type	
Colorectal cancer	7
Breast cancer	4
Lung cancer	4
Lymphoma	3
Others ^a	5
Therapy type	
Chemo only	7 (36.8%)
Chemo and surgery	5 (26.3%)
Chemo, radiation, and surgery	2 (10.5%)
Others ^b	5 (26.3%)
Time since diagnosis	10 (8)

^aOther cancer types involve ovarian cancer (1), polycythemia vera blood cancer (1), endometrial cancer (1), prostate cancer (1), and cervical cancer (1). Four participants had more than one type of cancer

^bOther types of therapies involve surgery only (1), chemotherapy and radiation (1), surgery and radiation (1), chemotherapy and stem cell therapy (1), and chemotherapy, radiation, stem cell therapy, and immunotherapy (1)

Table 2Participants'descriptions of PA duringcancer treatment

various cancer diagnoses. Most identified as female (90%) and were employed (56%). All participants had completed cancer treatments; most received chemotherapy only (36.8%) or a combination of surgery and chemotherapy (26.3%). See Table 1 for other participant demographics.

PA engagement during and after treatment

During cancer treatment, participants engaged in diverse PA (Table 2). Participants who attempted to stay physically active during treatment shared that they were physically active prior to their cancer diagnosis. Participants talked about needing to conserve energy for basic needs on treatment days. They recalled walking laps in the oncology patient unit and doing leg exercises in their hospital bed. When asked about PA levels during treatment, they struggled to detail how many days per week or an average of how many minutes they were physically active. However, examples of their activity indicated that few were able to engage in the commonly advised 150 min of moderate activity per week [22].

Participants explained that PA remained challenging posttreatment. No participants expressed certainty or knowledge about recommended PA guidelines for cancer survivors. All participants indicated that they were currently trying to do some PA; this ranged significantly—from consistent structured workouts every day to being active around their home or garden. Participants' responses revealed barriers and facilitators to PA engagement both during and after cancer treatments as described below and presented in Table 3.

Barriers

PA barriers during treatment

Treatment side effects Participants spoke of treatmentrelated side effects that impacted their ability to do PA, including fatigue, pain, nausea/vomiting, loss of appetite, anemia, compromised immune system, and vision challenges. Some participants indicated that they took a break from PA to recover from cancer-related surgeries or that being immunocompromised impacted their ability to do

Type of PA	Amount of PA
• Walking	● 20–30 min of jogging 3× a week
 Jogging 	• 3 miles per day
Stretching	• $1-2$ miles when possible
• "Doing something"	• 1.5 h daily for about 5–8 h a week outside with pets
Bike riding	• Doing "some type of thing" at least twice a week
 Walking stairs 	 Climb up the stairs ten times a day
 Taking care of/walking pets 	Walk a mile
Physical therapy	

Table 3 Barriers and facilitators to PA during and after cancer treatments

During treatments	After treatments

Barriers

- Treatment side effects: "I had no motivation at all for exercising... you're just tryin' to make it through a day. The fatigueness that goes along with chemo is unsurmountable."
- Decreased psychological well-being: "It becomes very emotional and psychological too 'cause I got to want to move....You get these anger things."

Facilitators

- Family: "[Walking with] my sister... it's easier...because they're your motivation really...It just makes it a little bit easier, not really thinking about all the pain or anything that's going on."
- Faith/God: "faith— mentally, physically, through the whole thing it kept me going, my faith... My faith in God, it just played a big part."
- Survivor support: "I started to go to blogs where the cancer patients who did the impossible, the ones that were waking up in the morning going, "I'm in pain. I'm struggling. I vomited for the morning, but I'm still gonna go out there and do my three miles." I would mentally get prepped"
- Managing side effects: "when I ran, again, the sweating, the physical activity, my hot flashes decrease[d]" and "I didn't really experience as much pain as my other counterparts... I think it had a lot to do with my physical activity."
- Setting small and realistic goals: "That surgery was very painful... so I was recuperating from that, and then...I had that chemo, so I wasn't able to do much of nothing...the first day, I walked up and down the driveway a couple of times and I sat down in the car and I rested. The next day I walked a little further, so every day I walked a little further."

• Long-term cancer and treatment effects: "the fatigue… has lasted since the diagnosis, and I think it just gradually progressively got worse, honestly. Chronic fatigue does also impact my desire to be more active, as well as just the ability to do it."

- Psychological trauma: "There is PTSD. It's so much to process... I was totally fit...and look what happened. If I go back to doing that, am I gonna get cancer again? What if I injure myself and I break something... and I never heal the same way, and now I've added another pain to my already insanely painful existence?"
- Competing demands: "I have a mother that is not in the best of health, and so there are things that I may have to do for her."
- Environmental barriers: "I wait in the morning until I see more people, more movement. If I happen to—for some reason I can't do it in the morning and I have to wait until the night, if it gets too late, then I'll say, 'Oh, it's too late now,' and I won't go over there at night."
- Family: "he [husband] says, "Hey you're my wife. I want you to be around for as long as I'm around," to do that, he says, "I want you to be healthy and I'm going to encourage you in that aspect.""
- Faith/God: "I put my cell phone on, go to my gospel music, and I just walk, walk, walk."
- Survivor support: "sometimes I meet up with...other [cancer survivor] friends of mine [to do PA] who have bonded...during the cancer journey."
- Empowering a sense of control over health: "I think of it as the mindset that I know I've done everything that I could... If I get cancer again, and I know I'm doing all the right and healthy things now, then I'm going to have a stronger mindset to fight it even more because I know that I'm doing things right."
- Striving for personalized PA goals: "I usually am able to meet my goal at least 5 days per week walking in the neighbourhood for usually between 45 minutes and an hour...at the end of it, my fitness tracker tells me how much of my exercise was cardio."

activities outside of their homes. One participant explained, "after surgery, took me about ... a month and a half to really feel less pain, to be able to continue my stretches and all that." Across participants, physical limitations from cancer treatments were consistently cited as limiting PA.

Decreased psychological well-being

Participants discussed emotions they felt during treatment that impacted their ability to do PA. Many revealed how their cancer diagnosis and subsequent treatment side effects led to feeling a loss of control, which was emotionally turbulent. This was especially troubling for those who were very active prior to having cancer; as one participant shared, "*I'm constantly movin'**Then all of a sudden, this entire illness*

platform overtakes my entire life." Participants also shared feelings of depression, anger, and irritability. Consistently, participants explained that these negative emotions impacted their motivation to attempt PA.

PA barriers after treatment

Long-term cancer and treatment effects Participants explained that even after treatment, they still felt physically limited to do PA. Long-term effects—fatigue, neuropathy, pain, and incontinence—were mentioned as specific barriers. One participant shared that sprained ankle due to neuropathy limited their activity; they explained, "*I actually don't feel the upper balls of my feet through my toes… I fall a lot.*" Other participants described fear and not wanting to

overextend themselves physically; after going through so much physical suffering, they "*just [didn't] like to put a strain on my body.*" Participant responses indicated that late and long-term cancer and treatment effects are unique barriers that survivors face in attempting PA.

Psychological trauma Participants expressed that "cancer is a trauma"; even after treatment, their poor psychological well-being still limited their PA. One participant shared that going through cancer so impacted their life that self-care seemed fruitless: "Well, what's the point? Why should 1?" Another participant explained they have anxiety because "once you've fallen once and you realize, oh, my God, my body is so weak...you really start to panic." Overall, participants were uncertain whether they could do anything, including PA, to lower their risk of suffering from cancer again; rather, some actually worried that PA may "trigger" cancer to come back or harm them in some way.

Competing demands Participants prioritized other things over PA, such as work, taking care of family, and paying medical bills. One participant shared that they simply "don't have time...when I get off [work] if it's dark." Participants shared that they needed to focus their time on taking care of family; for example, one shared, "I have a daughter. I'm a single mom, and so sometimes it's a busy day." Others talked about the prohibitive cost of gym memberships and needing to put money towards other things: "I'm paying all these medical bills. When I'm ready to join the gym, is that affordable to me?" Participants commonly shared that they needed to prioritize other things over spending time and money on PA.

Environmental barriers Findings revealed environmental barriers (i.e., weather and safety) related to where participants live that impacted their ability or desire to do PA. For example, one participant shared, "with the weather being cold right now, I'm at one time a week" and "the summer the heat—it's unbearable." Related to safety, participants discussed that they had concerns about doing PA outside. One participant explained, "You see things…in the news about everywhere you look, but it just causes you to be more conscious and aware of your surroundings." Across participants, the combination of both weather and safety concerns limited outdoor PA engagement.

Facilitators

Physical activity facilitators during treatment

Family Participants shared that their family uniquely supported them to be physically active during treatment; when

their family members encouraged them to move and offered to do PA with them, it made it "easier to get out there and do it." Another participant shared that they were motivated to take care of themselves so they could "be around for them [family]. I didn't stop bein' me. I didn't stop bein' a mother. I didn't stop bein' a wife. I just wanted to live, so I did what I had to do to live, whatever that meant." Across participants, family motivated PA engagement in multiple ways.

Faith/God Participants discussed the importance of faith and God during their cancer treatments, which guided their actions. One participant explained that their faith in God gave them strength "to do what I need to do," and that with this strength, "the body will follow." Another participant stressed the importance of faith to them: "again, I can't say enough how much my faith pulled me through this." Overall, participants noted that faith was a significant and powerful part of their lives to consider in regard to anything they were faced with or attempted during cancer treatments.

Survivor support Participants shared that they got inspiration and strength to do PA from other cancer survivors via blogs, word of mouth, and connecting with other survivors to do PA. One participant shared that they felt motivated to walk when they "*read a couple positive ones* [blog posts] *that said, 'Look, you just have to put your big girl panties on, on your good days. Embrace those days.*" Another participant shared that being "*matched*" through a cancer support organization with another cancer survivor "*motivated me to do it* [PA] *because it would help me feel better.*" Hearing positive talk from other survivors about PA was an effective motivator for participants to try and engage in PA during treatments.

Managing side effects Participants shared that when they did PA during treatment and noticed that it helped with side effect management, it motivated them to do more. One participant explained how they remained engaged in PA when they "started to realize yeah, the more I walk and the more miles I did, I was helping get rid of the chemo in my system." Another elaborated that when they "started to do it [PA] consistently every day for at least six days a week," they noticed more benefits: "every time I did more, I felt better, I got stronger, I was more in control of my body, my functions, my head space." Overall, experiencing the benefits of PA served as a facilitator for participants to do more PA during cancer treatments.

Small and realistic PA goals Participants discussed that the PA they engaged in during cancer treatments was variable and that they needed to set small goals that were realistic while receiving treatments. Participants shared that during treatment, their PA might start with basic daily activities; as

one indicated, they simply "*walked up and down the driveway a couple of times.*" Participants also expressed a need to rest and take a break from trying to do PA when needed; one shared that they felt "*It's okay to lay in the bed for two to three days if you're not feelin' well.*" Generally, participants found that small, flexible PA goals during treatment supported their continued efforts.

Physical activity facilitators after treatment

After completing cancer treatments, participants indicated that their family, other survivors, and faith continued to support their engagement in PA, similar to during cancer treatment. Additional post-treatment PA facilitators were noted by participants, including using PA to provide a sense of control over health and striving for PA goals.

Empowering a sense of control over health Participants shared that doing PA after going through cancer treatments gave them an enhanced sense of control over their health and life. One participant shared that they liked "knowing this is an area where I can take control, and it should positively impact the outcome, [doing PA] was me taking a little bit of that power back." Participants expressed that PA was part of their recovery process not only in feeling better but also in feeling more control over their health.

Striving for personalized PA goals Participants shared that setting and achieving personalized goals helped them to engage in and continue their PA after treatment. They used personal goals to progress their PA, which meant it "may be at a different rate than someone else." Participants discussed how they just tried to "do more than what I did before." They also discussed using technology such as an Apple watch or Fitbit to track their activity; one participant shared " [I] don't stay in one spot all day... I have an Apple watch so it tells me if I've been sitting too long...if my watch tells me to get up, I get up." Generally, when participants completed cancer treatments, they became more focused on setting and achieving PA goals.

Influence of the COVID-19 pandemic on PA

Most participants thought the COVID-19 pandemic negatively impacted their ability to be physically active. Participants talked about how the pandemic limited their sources of support: "*it was beginning of COVID when I started chemo, and so my husband… was mainly my support system.*" Participants also talked about the impact of reduced access to fitness facilities: "*I need someone else to push me. I need a trainer.... That* [Covid-19 pandemic] *crashed everything.*" Additionally, participants discussed that their increased health concerns as cancer survivors put them at greater risk for going to fitness facilities, so they "had to think of places to exercise where [they] would not encounter a bunch of folks." Across participants, many referenced the impact of the pandemic in lessening their support, motivation, and facility access for doing PA.

Discussion

Findings from this study identify barriers and facilitators that Black/AA cancer survivors experience in trying to do PA both during and after treatment. Because Black/AA survivors experience worse cancer outcomes and do less PA compared to White survivors and have historically lacked tailored PA interventions, our findings contribute crucial insights for future intervention development. This study identified significant environmental barriers to outdoor PA, including weather and safety. While these are common PA barriers across diverse populations, they may be especially problematic for Black/AA cancer survivors. Our findings indicate that cancer-related medical bills impacted participants' ability to pay gym memberships. Thus, survivors' PA options may be limited to free public spaces. However, participants were hesitant to engage in outdoor PA due to safety concerns heightened by news reports. This research was conducted immediately following global pain and outrage after Ahmaud Arbery was killed while running in a predominantly White neighborhood. Consequently, racism-related safety concerns that Black/AA individuals may face in doing outdoor PA would have been frequently in the news. Limitations to outdoor PA are especially problematic when gym memberships are not affordable. Additionally, one recent study found that outdoor PA may lead to more psychosocial benefits for cancer survivors compared to indoor PA [26]. Thus, multi-level, structural interventions are needed that not only target the individual level to motivate Black/AA individuals to do PA but also focus on creating new policies, systems, and structures to change the social environments in which individuals live.

Fear that PA may in some way "trigger" cancer to come back or cause harm was another PA barrier noted in this study. This has not been noted in other studies. Several national cancer organizations have created PA guidelines and patient resources based on decades of research that PA is safe and beneficial for cancer survivors [22, 27]. Future work should focus on assessing the cultural appropriateness and distribution venues of these materials, specifically for Black/AA individuals. Successful community education efforts may include developing partnerships with community organizations such as church ministries, fraternities, sororities, and cancer support groups to co-create and deliver community health education focused on the role of PA in cancer prevention and control.

Findings indicate the role of family as a PA facilitator both during and after cancer treatments is especially important to consider in interventions for Black/AA cancer survivors. This finding is supported by the work of Cho et al. (2020) [28], which indicates that lifestyle interventions for AA prostate cancer survivors should include the participants' wives because they guide health-related decisionmaking and are survivors' central sources of support. In the present study, participants valued that their family understood their capabilities; they also trusted family encouragement to do PA. Notably, the medical system is not trustworthy for Black/AA patients due to centuries of neglect and abuse [4, 29]. Thus, while research has indicated that oncology healthcare providers are a preferred source of PA encouragement among cancer survivors, this research has been largely conducted with White [30, 31] and Asian participants [9]. Findings from this study indicate that the role of family members may be especially important in PA interventions for Black/AA cancer survivors.

Finally, the role of faith and God was noted as a powerful PA facilitator in this study. The importance of faith in PA interventions for Black/AA individuals not diagnosed with cancer has been noted [32–34]. However, researchers inadequately understand the unique role of faith and God for specifically Black/AA cancer survivors. In one study of 65 AA and non-Hispanic White breast cancer survivors, 53% of AA participants (compared to 23% of NHW participants) indicated that religious faith facilitates PA engagement. Together, these findings indicate that PA interventions for Black/AA cancer survivors should incorporate considerations of faith.

Findings from this study need to be interpreted in the context of study limitations. First, while the strength of this research is that it includes diverse perspectives from survivors of a variety of types of cancer, it must be noted that the sample consisted primarily of women with high-education levels. Additionally, all participants had completed cancer treatments and were asked to recall their memories of treatment and PA experiences. Furthermore, participants were on average 10 years post diagnosis; thus, PA facilitators and barriers in the early months and years following treatment may not be captured in these findings.

Conclusions

PA interventions that are responsive to barriers and facilitators identified by Black/AA cancer survivors should be developed to help improve cancer health outcomes in this population. To optimize the impact of such interventions, they should be implemented as soon as possible after cancer diagnosis and should include flexible, adaptive goals that are responsive to the treatment-related barriers. Effective PA interventions for Black/AA cancer survivors are likely those that focus on policies and systems change rather than only traditional individual-level behavior change; disseminate research about the safety and benefits of PA to cancer survivors; and include the importance of family and faith in behavioral decisions. These findings are also immediately relevant to clinicians, who may consider these factors when supporting Black/AA survivors to engage in PA as a way of improving their cancer health outcomes.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s00520-023-07601-0.

Authors' contributions Authors R.H., R.T., J.C., K.G., A.H., M.W., S.B.W., C.G.V., A.L.B., D.F.L., J.L.M., P.D., and K.C. contributed to the conception and design of the research study. Authors T.T., R.T., J.C., K.G., A.H., and M.W. contributed to the data collection. Authors R.T., J.C., K.G., A.H., M.W., R.H., J.X., D.F.L., J.L.M., P.D., and K.C. contributed to the data analyses and interpretation. All authors contributed to, reviewed, and approved the manuscript submission.

Funding Author R.H. received research grant from Oncology Nursing Society (RE01) and National Institute on Minority Health and Health Disparities (K23 MD015719-01) to support this work.

Declarations

Ethics approval This research study is approved by the Institutional Review Board (IRB no. 19-3299) at the University of North Carolina at Chapel Hill.

Consent to participate Participants provided verbal consent before being interviewed in this research study.

Consent for publication There is no personal data included in this manuscript.

Competing interests The authors declare no competing interests.

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