

NARRATIVE SECTION

1. Outputs, Goals, & Objectives

Our READS grant application proposed several activities, with a focus on education and research. **We confirm that the proposed activities were indeed completed.** Here we present the statement of rationale and objectives from the grant application, along with a report of associated activities and outcomes.

Statement of Rationale (from grant application)

To improve cancer prevention and control in Ethiopia, greater community awareness of cancer will be essential for increasing uptake of cancer screenings and cancer treatment. This moment in time is critical for cancer-related initiatives in Ethiopia, as the government has recently dedicated significant efforts and funding to systematically addressing cancer for the first time in the country's history. With policies and programs newly established, many communities now have access to preventive and curative cancer services for the first time. Still, health providers report that low community awareness is a major barrier to the uptake of these services. In addition to lack of awareness, prevalent and persistent misconceptions about cancer provide fodder for cancer stigma and discrimination. Empowering cancer patients and survivors to share their stories and lived experiences is one way that cancer can be humanized, combatting misconceptions and increasing cancer awareness with conversations about cancer extending beyond clinical spaces and into the community through a multi-media educational campaign leveraging locally relevant cancer information.

As cancer services expand, best practices serving cancer patients and survivors should be formally evaluated and disseminated in Ethiopia. The first-of-its-kind breast cancer support group in Adama has potential to be scaled up across Ethiopia and other low-resource settings. Anecdotally, participants in this group report improved sense of overall well-being, though the effectiveness of the new program has yet to be evaluated. With data about the impact of the group on participant's quality of life, this patient service can be promoted, disseminated to other health facilities and locales, and improved over time.

Aims & Objectives

Aim 1: Support Group Educational Aim. Concerted effort to improve the quality of the support group's educational capacity will include procurement of a computer, a projector, and basic educational supplies for the group as well as promotion of improved content through curation of standardized (accurate, reliable, relevant) educational materials and resources and guest speakers.

- *Objective 1.* To bolster the support group's capacity to serve its members by availing equipment, high-quality educational materials, and content experts.
- **Activities and Outcomes.** The group's infrastructure was improved through procurement of a laptop computer and an LCD projector which are used to display slide presentations during monthly psychosocial support group meetings, and which can also facilitate virtual participation of experts. Local content experts were invited to attend six of the monthly meetings and to present on different topics of interest to participants, such as nutrition for cancer survivors. We provided these experts an honorarium as compensation for their time. Also vital to the functioning of the support group is the peer leader, Emmabet Asfaw. We compensated Ms. Asfaw for her leadership and organization.

Aim 2: Community-Based Educational Aim. Educational materials featuring support group members and facilitators will be created and disseminated in a multi-media cancer awareness raising campaign across the Oromia region and nationally in Ethiopia.

- *Objective 2.1.* To create contextually-relevant cancer educational materials that are accessible to a wide Ethiopian population, using local language, culture, and data to facilitate greater community awareness of cancer including what cancer is, common signs, symptoms, and risk factors, how cancer can be prevented and effectively treated, how to navigate local health services, and confronting popular myths and cancer stigma.
- *Objective 2.2.* To empower breast cancer patients and survivors to share their lived experiences, providing a platform for their voices to be raised, and to increase opportunities for patient and survivor advocacy by legitimizing their experience and engaging key stakeholders such as hospital administration, policy makers, and Ministry of Health officials with their collective stories.
- ***Activities and Outcomes.*** We worked with a consultant to create culturally- and linguistically-relevant breast cancer education materials and then distributed these materials in a far-reaching mass media campaign. These included pamphlets (n=3,000) and instructional videos that included information on conducting breast self exams, which were distributed in person, displayed on digital monitors in banks and digital billboards in strategic community locations, and shared on social media. On social media, paid Facebook ads generated over 16,000 engagements with the post also being shared by the Hakim Facebook page, with more than 200,000 followers, amplifying its impact. Awareness raising banners (n=30) were displayed in prominent locations in the community in Adama. Dr. Biniyam Tefera (Oncologist) and Ms. Emmabet Asfaw (Survivor) were interviewed on local and national TV and radio programs, where they shared information about cancer prevention, signs and symptoms, promoted screening, and shared about the lived experience of surviving cancer. Four national TV interviews, broadcast through Ethiopian TV (ETV), Walta TV, Oromia Broadcasting Network (OBN), and other prominent networks, had a reach with a magnitude in the tens of millions, although the true reach is unknown. Radio interviews were particularly accessible for rural audiences and one radio program included an interactive Q&A segment where community members could call in to speak with Dr. Biniyam live on air. A smartphone application that walks women through breast self-exams was translated into the local language and was promoted at the community screening event.

Link to Walta TV Interview on YouTube: <https://www.youtube.com/watch?v=kgbPJD-xXrE>

Link to ETV Interview on YouTube: <https://www.youtube.com/watch?v=Ph71uhA1SGA>

In addition to the awareness raising campaign, we hosted weekend community-based breast cancer screening events in October 2022 in two communities (Adama and Mojo) to the southeast of the capital city, Addis Ababa. These community-facing events included breast cancer education delivered by cancer survivors, giving the women a platform to speak to the wider community as well as strategic community leaders and health stakeholders who were invited to the events as part of a celebration for Breast Cancer Awareness Month. A total of 525 individuals attended the events and were screened for breast cancer with a clinical examination. Among them, 33 suspicious nodules were detected and additional ultrasound screening, of which 13 were then referred for fine needle aspiration cytology (FNAC). One case of early-stage invasive cancer was detected.

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- 02 ይመልከት**
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- 03 መደሰስ**
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- 05 ባሳት**
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- 07 በወገን በመገንጠል**
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- 08 ገላግን ስተጠብ**
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Tasgabaa'aa Rakkooleen harma irratti mu'atan baay'een isaanii kan balaaf nama saaxilanii miti. Marsaa lammaffaaf harma keessaan irra deebilin sakattaa'aa

Waan adda ta'e Hubattanii jirtuu?

Osoo hin rifatin wantoonni ilaaluu qabdan

Dhiitaa

Dhiitaa, wanti jabaataa yookin kardaa harma irratti bakka hunda irratti waan uumamu danda'uuf ilaalamuu qaba. Kuniis harma irratti yoo muf'ate mallattoo kaansarii ta'uu danda'a.

Jijjiirama hammaa/boca

Hammaa fi boca hin baratanne yoo argitan ilaalamuu qaba. **Wanti beeku qabdan...** Harma bilaa fi mirgaa uumamaan hammaan gar gar ta'uu danda'u. Garuu wanta yeroo biroo irratti adda ta'e yoo argitan ilaalamuun barbaachisaa dha.

Jijjiirama Gogaa

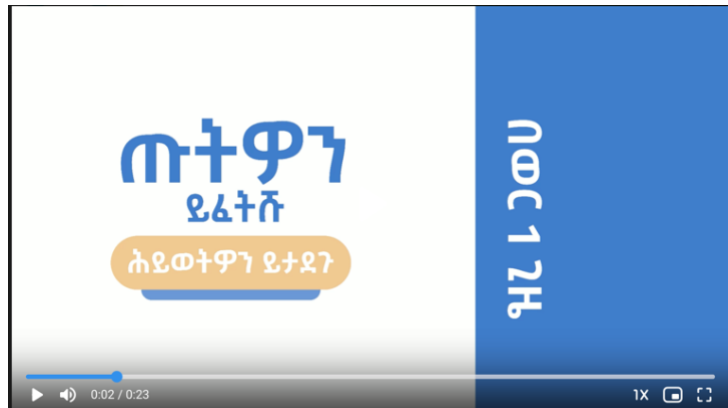
Jijjiirama gogaa kan quunnee burtukaanaa fakkaatu yoo argitan, gogaan harmaa kardaa ta'uu, diimachuu, dhukkuba yookin ciltos, irra jiree ammoo harma tokko qofa irratti yoo muf'ate ilaalamuu qaba.

Dhangala'aa mucha irraa ba'u

Dhiga yookin dhangala'oo biraa mucha irraa ba'u yoo muf'ate ilaalamuun barbaachisaa dha.

Mallattoolee armaan olii yeroo argitan gara Dhaabbata fayyaa naannoo keessan jiru dhaqaa

Digital breast self-examination app translated into Amharic (left) and tutorial video in Amharic (right)



“Pop up” breast cancer screening event in Adama, October 2022



Aim 3: Research Aim. The effectiveness of the breast cancer support group will be measured by comparing the self-reported quality of life (QOL) of support group participants with the self-reported QOL of non-participants through a facility-based survey administered to 50 patients at Adama Hospital Medical College and Tikur Anbessa Specialized Hospital (control facility).

- *Objective 3.* To objectively evaluate the perceived impact of the breast cancer support group on the lives of women diagnosed with breast cancer.
- **Activities and Outcomes.** As part of a larger study for which Dr. Biniyam Tefera Deressa was funded as a Global Health Equity Scholar (mentored by Drs. Purnima Madhivanan and Breanne Lott), we surveyed breast cancer patients and survivors in Ethiopia to measure their quality of life using multiple measures. A total of 305 responses were recorded (of which 50 participants were compensated through the AACE grant), including 48 support group participants and 257 non-participants. The data are currently being analyzed. So far, we only have descriptive statistics to share on the quality of life for all respondents and have not yet concluded whether the psychosocial support group improves self-reported quality of life. We plan to publish our findings and will be happy to make the article available at a later date. The figures below show how our respondents reported distinct components of their quality of life. As seen in Figure 1, they scored their physical health highest and social health lowest. Specific symptoms that impact their quality of life include fatigue, nausea, and pain (Figure 2).

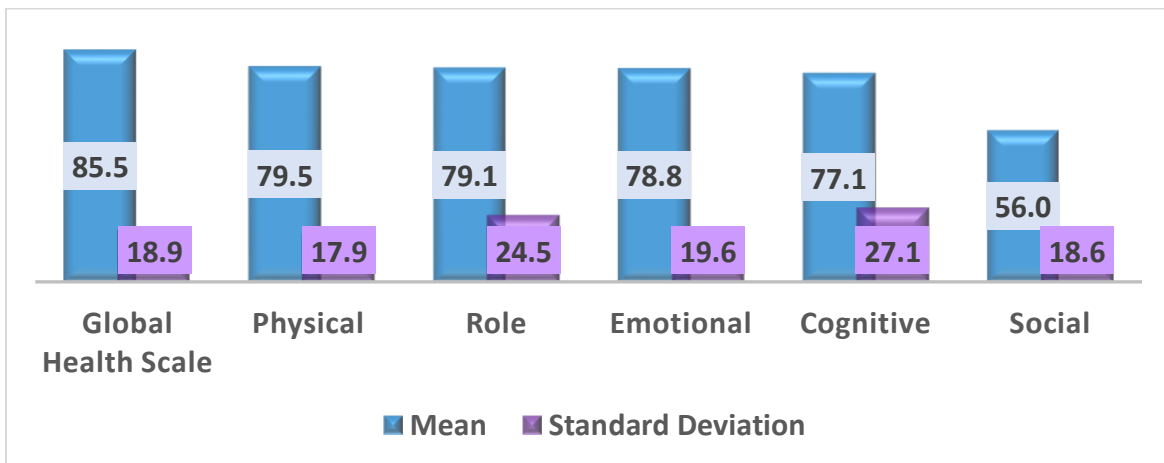


Figure 1 Summary of global health & functional quality of life scores of breast cancer patients treated at Adama hospitals medical college and Black Lion hospital, 2023, Ethiopia

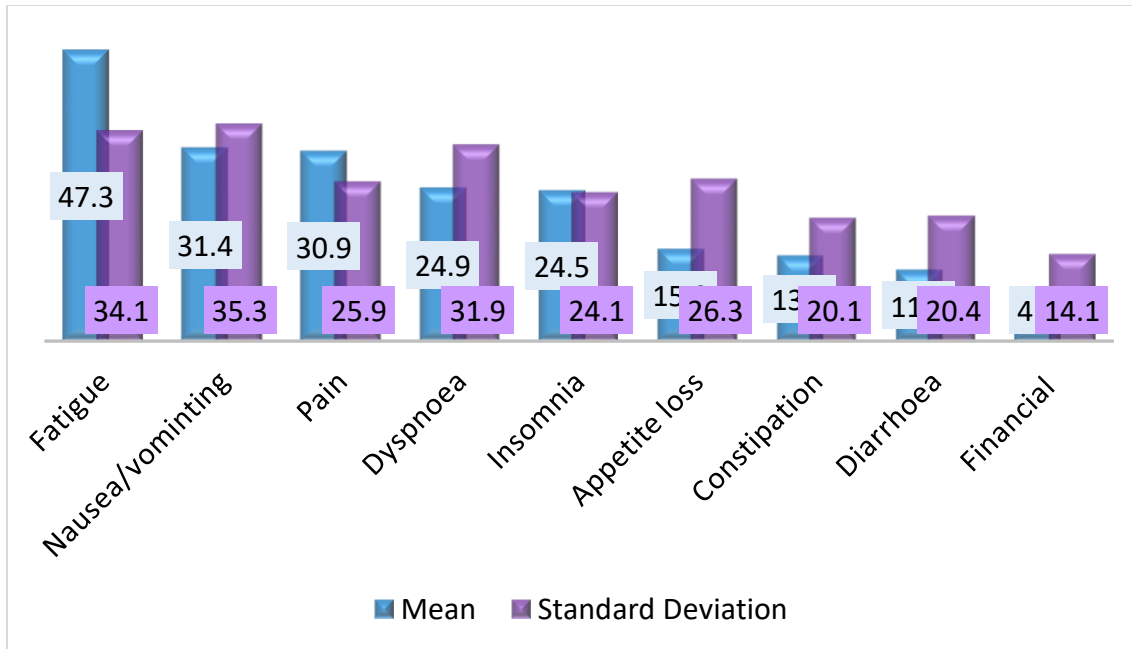


Figure 2 Summary symptoms quality of life scores of breast cancer patients treated at Adama hospitals medical college and Black Lion hospital, 2023, Ethiopia

2. Lessons Learned

We have learned a number of lessons through this project. Firstly, we recognize the power of culturally- and linguistically-accessible cancer education materials. Through a multi-media campaign, we were not only able to educate the masses about breast cancer, we were able to sufficiently motivate more than 500 individuals to heed the call to action and to get screened themselves. Secondly, the community-based “pop up” screening event model we used to take screening out of a clinical setting and host screening events in centrally-located community spaces in tents worked extremely well. We hope to explore this model for future cancer screening initiatives in Ethiopia. Thirdly, our engagement of breast cancer patients and survivors proved to be especially impactful, with many community members commenting on the weight that the lived experience added to the cancer awareness raising messaging. This is why it is so important to empower and uplift survivors to organize themselves so that they are in a position to assume even greater education and advocacy efforts in the future.

Additional lessons learned are being shared in a drafted manuscript, which we plan to submit to Journal of Cancer Education, as described in Dissemination Plans (Section 4).

3. Career Impact

This collaborative project was led by two junior investigators (Drs. Biniyam Tefera Deressa and Breanne Lott) and their shared mentor (Dr. Purnima Madhivanan). For the junior investigators in particular, this project provided an opportunity to build skills in grant-writing, data collection and analysis, community engagement, and program evaluation. It gave us the opportunity to develop infrastructure which we will be able to use in future collaborations. It also gave us the opportunity to strengthen our partnership and to learn how to administer grant funds between our institutions. In part due to this experience, we have

been able to collaboratively apply for additional funding opportunities, including an NCI grant application submitted in December 2023. Also important to the collective career impact of this award are the scholarly products that have been produced as a result, as described in Dissemination Plans (Section 4).

4. Dissemination & Funding Plans

We are planning to disseminate our findings via peer-reviewed publications and conference presentations. These include one oral presentation at ICEC and one manuscript currently in development for submission to JCE's special collection on "Cancer Education Empowering Indigenous Communities".

- a) **Lott, B.E., Tefera, B., Madhivanan, P.,** Bekele, E., Muktar, S., Birhanu, F., Hussein, R., Mengiste, T., and Asfaw, E. (2023). Coming together for coffee, community, and cancer education: How breast cancer survivors are advancing awareness, care, and advocacy in Ethiopia. International Cancer Education Conference 2023. Toronto, Canada. [Oral Presentation]. Abstract available at: <https://link.springer.com/article/10.1007/s13187-023-02359-9>.
- b) Lott, B.E., Yeo, S., Bekele, E., Birhanu, F., Hussein, R., Muktar, S., Mengiste, T., Asfaw, E., Madhivanan, P., Tefera Deressa, B. Empowering Ethiopians to take action against breast cancer: evaluating a community-based breast cancer awareness campaign and screening event using the RE-AIM framework. [In Progress, planned submission to Journal of Cancer Education].

A third product will be a manuscript presenting the quality of life results, which are currently being analyzed (this manuscript is not yet in development but planned). Finally, we do plan to apply for additional funding in the future. Building on the work facilitated by this grant, we were able to identify several needs of cancer survivors in Ethiopia that we would like to address in the future. In March 2024, we will submit two letters of intent for a Pfizer and ASCO/Conquer Cancer quality improvement grant.