



Implementing an Occupational Therapy Intervention to Support Young Caregivers of Cancer Survivors

Njelesani, J., Ph.D., OTR/L, FAOTA
NYU Steinhardt Department of Occupational Therapy

Learning Objectives

1. Provide an understanding for how YCare is adapted for the cancer practice setting to support young caregivers in cancer care for family members
2. Describe the role of occupational therapists in supporting young caregivers of cancer survivors

Introduction

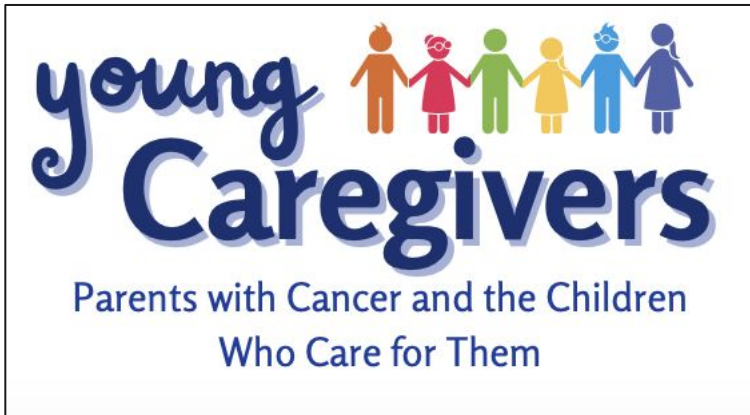
Occupational Therapist Role in Oncology

Occupational therapists (OTs) work with cancer survivors and their families to enhance their quality of life and enable occupational engagement.

Introduction

Young People's Role in Caring for Parents with Cancer

Young people are giving care with limited or no training and are not receiving intervention, support, or assistance from health providers.



Research Objectives

To advance OT cancer practice, the aim of this study is to adapt contents of YCare to an OT cancer practice setting.

Design

- This implementation study was guided by the Consolidated Framework for Implementation Research (CFIR)
- OT practitioners, children of cancer survivors, and cancer survivors participated in one-one-one semi-structured interviews
- Data were analyzed with Taguette qualitative analysis software using content analysis methods.

Consolidated Framework for Implementation Research (CFIR)

The CFIR guided measurement of YCare implementation for OT cancer practice settings, including measuring the inner setting (culture, tension for change, compatibility, access to knowledge and information), implementation (context, planning, strategies, deliverers), and individual/team characteristics (implementation, facilitators and team members, need, opportunity).

Participants

19 OT practitioners, 10 children of cancer survivors, and 12 cancer survivors

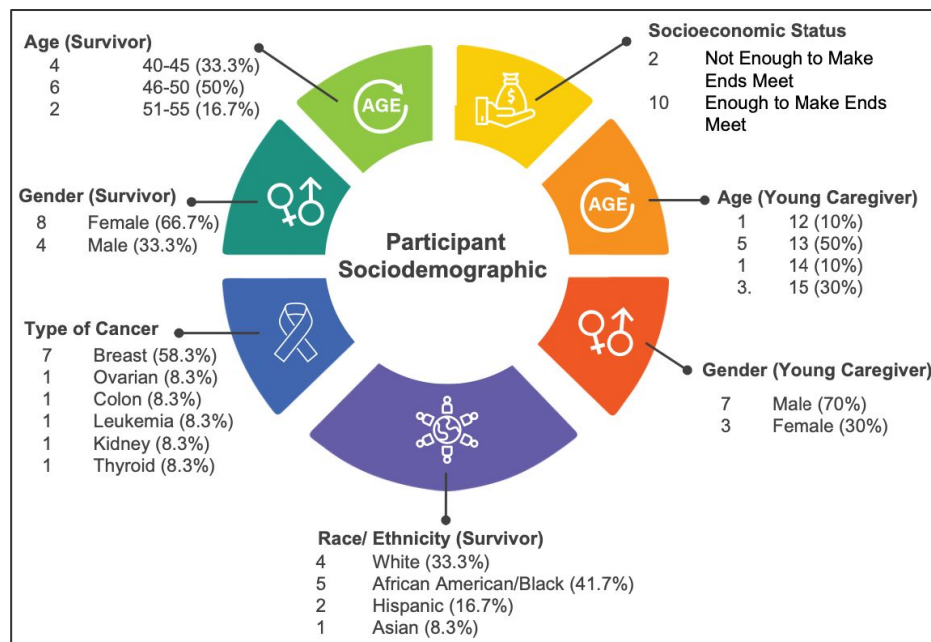
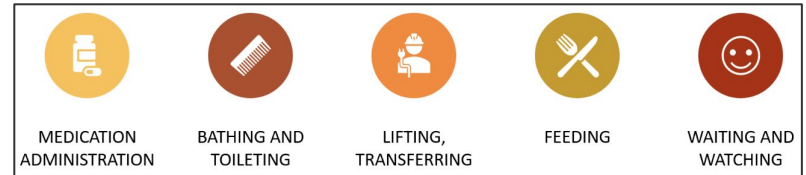


Figure 1. Youth & family participant demographics

Intervention

- YCare is an evidence-based group intervention where youth are provided with hands-on learning to support them with caregiving roles.
- YCare was originally created for those with neurological conditions, and adapted in this study to be applied and specific to the cancer setting



Occupational Therapist Quotes

"The electronic medical record has made it a lot easier to support them by (facilitating) communication amongst providers"

"If a patient is requiring physical assistance to transfer to their wheelchair, then the family needs to be trained in order to safely go home"

"If I call the caregiver and the patient is not in the room, I don't bill for it. If the patient is there in the room they can participate in the discussion and then I can bill for it"

Cancer Survivor Quotes

“She already knew she was getting ready to take care of me, that's why she asked questions and takes notes. The doctors never said, hey, you need X, Y, and Z or anything like that”

“I mean it's all meaningful to me, you know, because I couldn't do it. I can't do anything. I think anything that they do for me is meaningful”

“They need positive people. They don't need people trying to tear them down. They get enough of that already. Just positive reinforcement, therapy, good support system, family, things like that.”

Young Caregiver Quotes

"I didn't really understand the terms or whatever, all the medical terms they were talking about and stuff. That was just scary or whatever the way they were saying all of the medical terms and everything 'cause it seemed like it was complicated and stuff."

"There was already things goin' on at school, meetings here, and trying to make somebody proud, it's not always that easy. Nobody promised it was gonna be easy. It's hard, but I'ma just have to learn how to get through things"

Don't make things miserable for them 'cause, sometimes, they can be really trying and trying, and sometimes I understand people wanna give up. Just don't do things, intentionally, to hurt another person because they're already going through somethin'.

Results

- A flexible approach to intervention content is needed given how cancer presents differently across individuals.
- OT practitioners must support emotional and social needs of young caregivers.
- To adapt YCare, key considerations include feasibility of hospital regulations and precautions, insurance reimbursement, and availability of young caregivers to attend programming during working hours.
- The adapted YCare will consider specific areas where intervention is urgently needed to strengthen provided services.

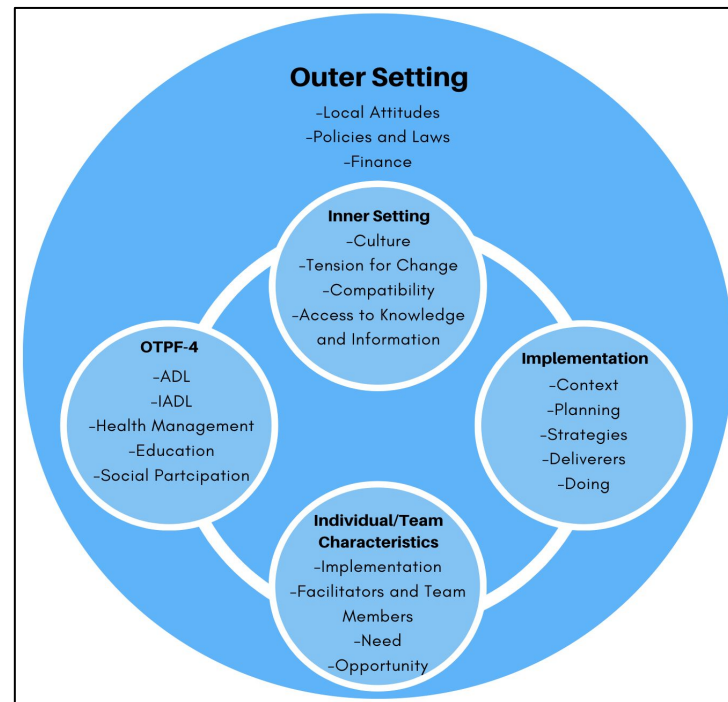


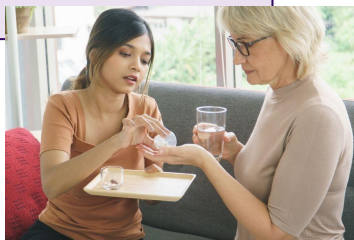
Figure 2. Pertinent factors to consider from CFIR and OTPF-4

Clinical Implications: Adapted YCare

Basic Care Skills

Techniques (like modifying activities, performing activities slower) to help your cancer survivor:

- **Dress:** Put on/off clothes and footwear, put on/off compression garments
- **Use Bathroom:** Get on/off toilet, into/out of bath/shower
- **Functional Mobility:** Walk to the bathroom, kitchen, etc., walk in the community, use a wheelchair
- **Take Medications:** How to help organize and remind them to take medications on schedule
- **Groom:** Brush teeth, shave, hair/wig care, put on scarves and turbans



Family Care & Roles

- How families transition into new roles and how to carry out new responsibilities (e.g., pay bills, make dinner, clean, grocery shop, therapy, etc.)
- How to do activities that promote emotional support, bonding, and quality time for families (i.e., taking walks, playing board games, etc.)
- Mental health strategies for coping with YOUR new roles



Health Management Advocacy

Develop advocacy skills including:

- Standing up for yourself
- Financial advocacy, health insurance coverage/billing
- Navigating the healthcare system

Develop skills to communicate confidently and ask relevant questions about:

- Cancer survivor's condition
- Appropriate care and safety measures
- Emotional support for family
- Community resources

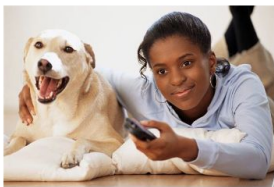




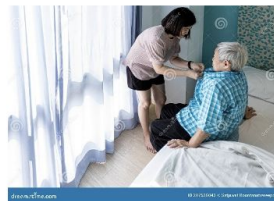
Cooking meals or helping to eat



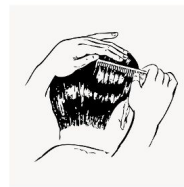
Paying bills



Taking care of pets



Helping dress



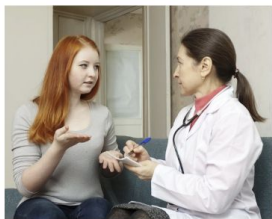
Helping with grooming



Helping walk



Grocery shopping



Going to or making appointments



Helping take medication



Cleaning the house



Helping use the toilet



Helping bathe/shower



Driving/taking public transit



Doing laundry



Taking care of young children



Helping with therapy

...and more
depending on the
young caregiver and
cancer survivor

Conclusions

With skills in educating caregivers and expertise in adapting daily activities, OT practitioners are well-positioned to support family needs and implement interventions that improve the skills young caregivers need to provide safe assistance and emotional support to cancer survivors.

References

1. Damschroder, L. J., Reardon, C. M., Widerquist, M. A. O., & Lowery, J. (2022). The updated Consolidated Framework for Implementation Research based on user feedback. *Implementation science : IS*, 17(1), 75. <https://doi.org/10.1186/s13012-022-01245-0>
2. Njelesani, J., Kavanaugh, M. S., & Hunleth, J. (2023). Adapting an intervention to support young caregivers of cancer survivors: A study protocol. *PloS one*, 18(4), e0284896.
3. University of Wisconsin-Milwaukee. (2023). Ycare. Retrieved April 6, 2023, from <https://uwm.edu/ycare/>

Questions?

If there are any questions, please contact:

- Janet Njelesani: janet.njelesani@nyu.edu