





Welcome!

May 19, 2022 8:00 am - 6:00 pm ET

#WCC22 #worldcarers



#WCC22 #worldcarers

Global Voices of Caregiving: A PhotoVoice Project

Lauren Tokarewich, MLIS, Research Manager, National Alliance for Caregiving, United States of America

Annie Levy, Chief Story Officer, United States of America





I am Shiang.

I am from Taiwan.

























In Loving Memory





#WCC22 #worldcarers

Share your vision for a world that includes and supports caregivers. Post a photo on Twitter or Facebook and use #WCC22 #carerstory and tag @NA4Caregiving to join the conversation.



#WCC22 #worldcarers

Promoting Mental and Emotional Health and Wellbeing



#WCC22 #worldcarers

Global Voices of Caregiving





I am Mami. I am from Japan.

















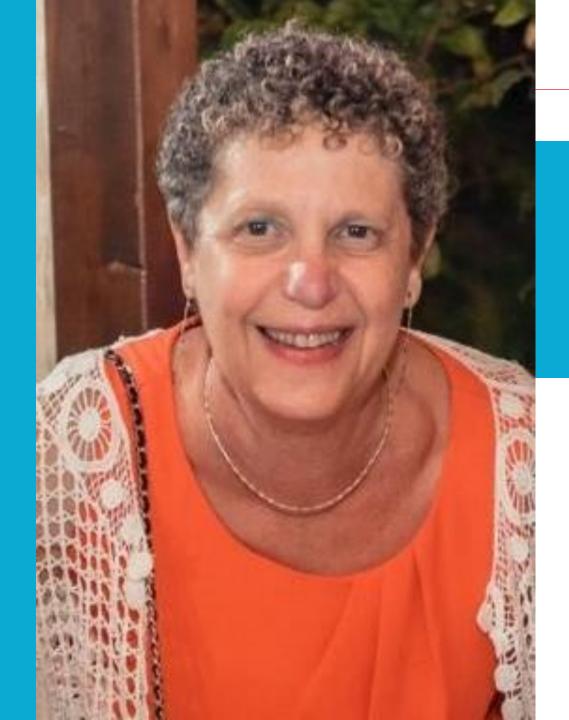




#WCC22 #worldcarers

Global Voices of Caregiving

Anat | Israel





I am Anat. I am from Israel.

I am Anat Elhayany but my mother still calls me Francoise because it is my birth name.

I changed my name into Anat when I decided to move and live in Israel at the age of 20.

My parents, sister and brother stayed in France, so my life and heart were always part in France and Israel.

My dad died 30 years ago after a short cancer and we really worried for my mom.





Anat | Israel

Although my mom was always the sick person in the family (she suffered all her life of depression and had to be medically treated), she remained a widow until now and reached the age of 100 six months ago.

I enjoyed 28 good years as a caregiver from far away, met my mother at least 4 times a year and talked with her almost everyday on the phone.





Anat | Israel

Things changed radically those last two years: her Parkinson's Disease went worse and she almost can't walk anymore and became dependent for everything.

As she says, it is making her feel she is a different person, trouble maker for all the people who take care of her at the residence she lives.

For me, it is very hard to see her changes, I feel I have to change myself too. I often ask myself whether it is worth it, what kind if a life it is for her and it makes me sad.

Of course, only I can visit her, she can't come to me anymore, so I travel to meet her every 3 or 4 months.





Anat | Israel

In the pictures, you see privileged and rare moments when she is well clothed and even with colour on her eyes and face, she can practice what she really likes: talking with a close person.

As we talk, I know that if I ask her a question about a period like the war in 1939-1945, she will start talking fluently and tell me a lot about situations she passed. For me, it is "drinking" her words and enjoying her as she used to be.

Unfortunately, she has problems to hear on the phone so it is hard to feel so unable to communicate daily.



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Global Voices of Caregiving

Vinicius | Brazil





I am Vinicius. I am from Brazil.

Hi! How are you all? My name is Vinicius. I am 25 years old. I am Brazilian and I live in São José do Rio Preto, in the countryside of São Paulo [state], Brazil.







Vinicius | Brazil

I have been a caregiver for 3 years for Beatriz Suzuki, my girlfriend [who was] diagnosed with colorectal cancer, who I met while she still had a colostomy bag.

I tried to show through the photos a little of what we went through in recent years. The treatment in a public hospital, the chemotherapy sessions, the surgeries and the use of a colostomy bag, which was part of our lives for almost 1 year.





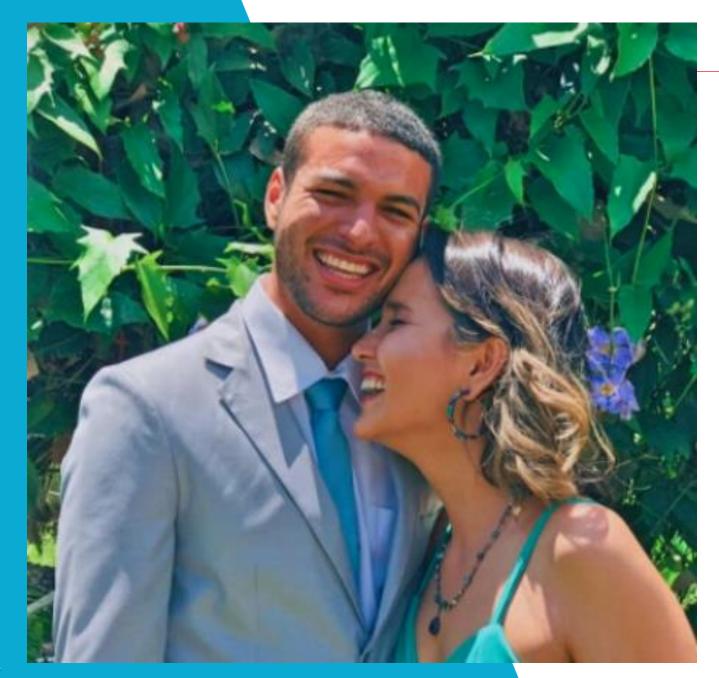


Vinicius | Brazil

During this time that Beatriz used the bag, the municipality provided only 10 per month and with very low quality. I could see that she was sad and didn't feel good about wearing them. To celebrate our anniversary, I gave her the best quality colostomy bag as a gift. She cried a lot with the gift and that was a turning point in our relationship.







Vinicius | Brazil

I dream of a world in which caregivers and cancer patients are not seen by society with pity. They should be seen like anyone else, with their ups and downs, good moments and difficult moments, just like anyone else.







Promoting mental health and wellbeing among adolescent young carers: the "ME-WE" European project

Elizabeth Hanson, Saul Becker (@profsaulbecker), Feylyn Lewis (@DrFeylynLewis), Lennart Magnusson, Miriam Svensson

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Young Carers/Young Caregivers



"Young carers are children and young persons under 18 who provide, or intend to provide, care, assistance or support to another family member or friend. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult.

The person receiving care is often a parent but can be a sibling, grandparent or other relative or friend who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision."

Saul Becker in The Blackwell Encyclopedia of Social Work Revised April 2022 to include 'friends' as a consequence of the ME-WE project

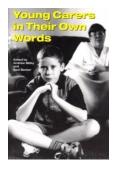
Young adult carers/caregivers are as above, but aged 18-24

Invisible Lives. Revealed 1990 – Today

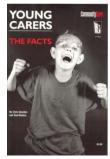






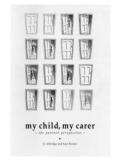


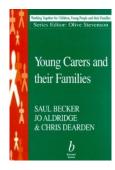






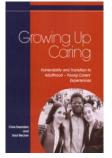


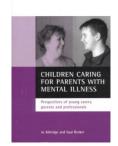


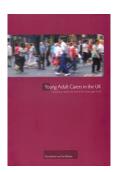












NOW – over 250,000 items on 'young carers' in Google Scholar

Becker & Leu Classification 2016, 2021





Leu, A., & Becker, S. (2016) A cross-national and comparative classification of in-country awareness and policy responses to 'young carers'. Journal of Youth Studies, 1-13.

Agnes Leu, Fabian Marc Pascal Berger, Malla Heino, Henk Herman Nap, Aurélie Untas, Licia Boccaletti, Feylyn Lewis, Daniel Phelps & Saul Becker (2022) The 2021 cross-national and comparative classification of in-country awareness and policy responses to 'young carers', Journal of Youth Studies, DOI: 10.1080/13676261.2022.2027899



ME-WE Project





Psychosocial Support for Promoting **Me**ntal Health and **We**ll-being among Adolescent Young Carers (aged 15-17) in Europe

January 2018 – June 2021

Sweden, The Netherlands, Italy, Slovenia, Switzerland, UK

ME-WE received funding from the European Union's Horizon 2020 Research and Innovation Programme under Grant Agreement No 754702

https://me-we.eu/

ME-WE Online Survey (2018/19)



9,427 participants

Of which, 7,146 aged 15-17



2,099 AYCs aged 15-17

70% female; 27% male



Who receives care?

69% care for family member [mum, dad, grandparents, siblings]

16% care for >1 family member

53% care for close friend

22% care for family AND friend

Grandparent care is highest in Italy [72% of 13% UK]

Family's health conditions

Physical disabilities 46%

Mental illness 40%

Cognitive impairments 26%

Addiction 10%

Friends: 69% have mental illness [82% UK of 30% Italy]

ME-WE Online Survey (2018/19)



General findings

Amount of caring (MACA) varies between countries

Female AYCs do significantly more caring in Netherlands and UK

Both positive and negative adaptation is found

AYCs have lower state of wellbeing (Kidscreen) than non-carers [females have lowest]

Higher levels of caring (MACA) are associated with > school difficulties, bullying, mental health

Impacts

29% say their own mental health has deteriorated [country range 12-57%]

17% say **school performance** negatively affected [country range 9-38%]

15% report being **bullied** [4-36%]

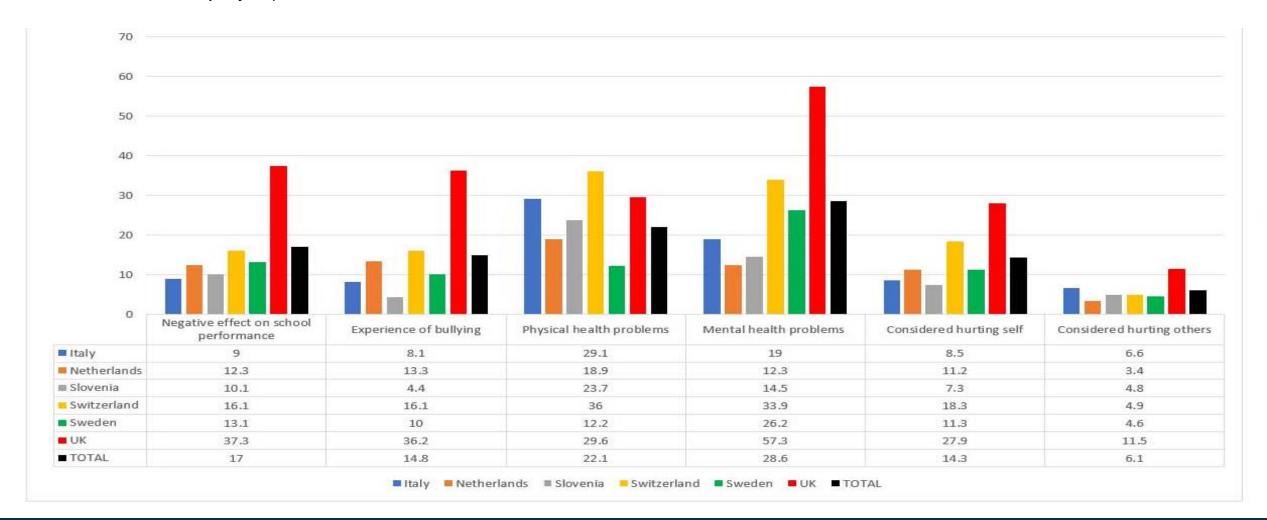
14% say they have thought about **hurting themselves** [range 7-28%]

6% say they have thought about **hurting others** [inc. person they care for] [range 3-12%]

What is the relationship between country-level responses and YC outcomes?



% of adolescent YCs who indicated they had experienced issues & difficulties due to their caring responsibilities (Source: Me-We research project)





Formal & Informal Preferences for Support

Respite care

- Time for leisure activities
- More free time

Emotional support

- Guidance from adults
- Opportunity to speak with professionals

Financial assistance

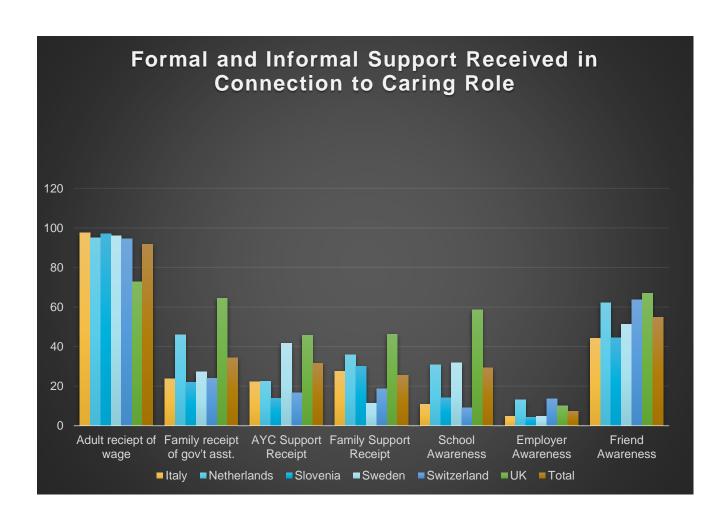
- Direct money payments
- · Aid to care recipient

Educational support

- Recognition of caring role
- Flexibility with assignments

Country-specific support issues

- UK: Desire for more service-related support
- Italy: Familial support needed
- IT/SI: Recognition of the state's role



ME-WE online survey – questions to the audience



- Are there other country contexts /global South, rural/farming locales) where this experience of adolescent carers might look different?
- 2. The presence of self-harming thoughts is often most alarming to professionals when we share our findings.....

How can we as researchers, advocates, and professionals create a safe space for young carers to speak out about the severe mental distress they may be experiencing? What is our role in lessening the stigma?

3. "Someone to talk to" and "help for the person they care for" stood out as a major finding when adolescent young carers were asked what would help them in their caring role.

How has your country sought to address the needs of adolescent young carers (if at all)? What do you think your country could do more of?





The ME-WE intervention

- Psychosocial support, primary prevention intervention.
- Consists of ME-WE groups (online or face-to-face) and the ME-WE young carers' mobile app.
- Co-designed and developed together with young carers and professionals working with young carers in all six partner countries.

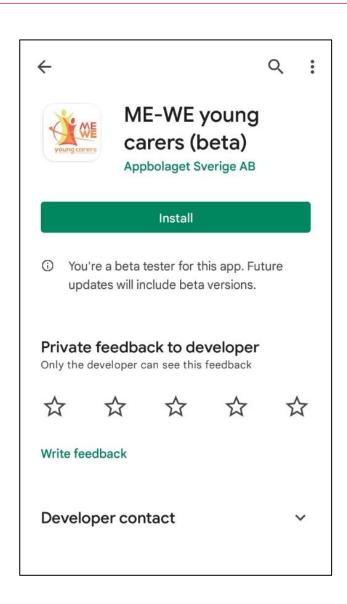
The ME-WE groups



- Based on the DNA-V model (Hayes & Ciarrochi, 2015), which has its roots in Acceptance and Commitment Therapy (ACT) and positive psychology.
- D = The Discoverer / N = The Noticer / A = The Advisor / V = Values.
- Focus: strengthening adolescent young carers' resilience, by providing them with tools to handle difficult thoughts, get in contact with and notice their own feelings, grow and flourish, find meaningfulness and strength/energy, develop a flexible self-image and build strong social networks.
- Consists of 7 group sessions (2 hours each, preferably one session per week), and a follow-up session after 3 months.
- Online or face-to-face sessions.

The ME-WE young carers' mobile app



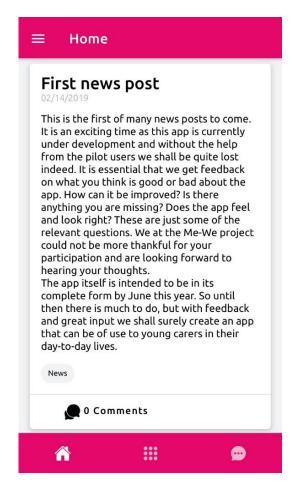


- Aims to deliver support for young carers at a distance.
- Is used in the ME-WE groups but can also function as a separate support for young carers who are not participants in ME-WE groups.
- Languages: Swedish, Italian, Dutch, Slovenian, German, French and English (i.e., languages spoken in the ME-WE partner countries).
- The app is publicly accessible at no cost via Google Play and App Store (in EU, EEA and EFTA states, and the UK).

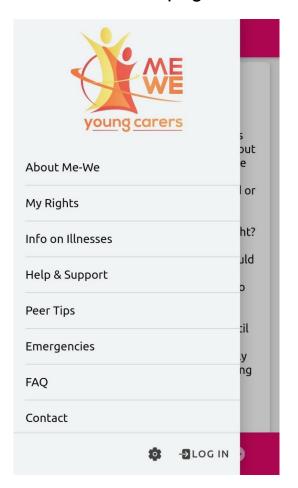
Key features of the mobile app



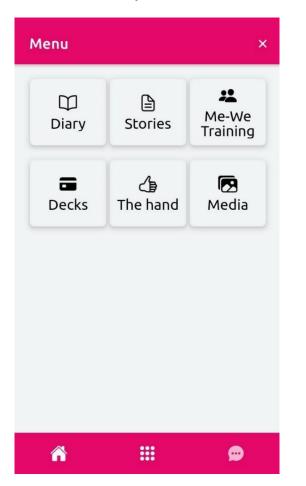
Home page



Information pages



Launchpad menu



Chat



ME-WE intervention evaluation results



- The ME-WE intervention has the potential of contributing to adolescent young carers' increased wellbeing and boosting their resilience.
- Many of the young carers enjoyed the group activities. They felt that they had been taught useful things and that the groups were worth going to. They said the groups made them feel good about themselves. Half of them felt the care recipient was better off because they had taken part in the groups.
- The intervention had a positive impact on young carers' school attendance and performance.
- The ME-WE young carers' mobile app was seen to be a potentially useful asset to the ME-WE groups, providing additional support to young carers.

ME-WE intervention – questions to the audience



- 1. What is your initial feedback on the intervention?
- 2. In what ways (if any) do you feel the intervention could be of potential benefit for AYCs in your country?

ME-WE 2.0 - activities post project



- The Swedish Family Care Competence Centre (Nka) is carrying out:
 - education for non-governmental organisations (NGOs) and municipalities who wish to start ME-WE groups with young carers.
 - coordination of online network
 meetings for ME-WE facilitators from
 different municipalities and
 organisations across Sweden to enable
 them to share their experiences and
 learn from each other.



Are you interested in the ME-WE intervention?



Our centre can offer:

- some educational materials in English.
- guidance to an online training course in the DNA-V model.
- opportunities to participate in online learning networks with Swedish municipalities and organisations working with ME-WE groups.





Transferability of ME-WE to other countries?

- WHERE?: Secondary school settings (middle school and high school) & youth organizations
- WHO?: Youth workers, group counselors, social workers
- HOW?: Identifying young carers/caregivers in your school or organization (ME-WE survey screening questions & MACA)

How could the ME-WE intervention work in YOUR respective country or organisation?

Thank you for your attention!



Contact details

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- @profsaulbecker

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- Email: feylyn.m.lewis@vanderbilt.edu
- Phone: +1 615-322 7980
- @DrFeylynLewis
- www.drfeylynlewis.com



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Global Voices of Caregiving





Hello, my name is Jean.

I am from Taiwan.

























Models of Support for Sibling Caregivers

Liv Mendelsohn, Helen Ries, Katie Arnold, Kate Strohm, Clare Kassa and Piyush Mishara

#WCC22 #worldcarers



Canadian Centre for Caregiving Excellence

Powered by the Azrieli Foundation



Land Acknowledgement

The office of the Canadian Centre for Caregiving Excellence (CCCE) is located in Toronto, TKaronto, on the traditional territory of the Anishinaabe, including the Mississauga of the Credit, Haudenosaunee, and Huron-Wendat. This land has been governed by the Dish With One Spoon Wampum Belt for a thousand years and in recent times by the Williams Treaty and Treaty 13.

All people living in Canada are treaty people; we are all a part of a relationship based on the recognition of respect, co-operation, partnership and Indigenous rights.

The CCCE is committed to equity for indigenous caregivers and care providers and to learning from and working with indigenous communities.



Our Vision

Canada leading the way in quality care, where caregiving is valued, caregivers are supported, and people accessing care are central to policies and practices.



Our Mission

The Canadian Centre for Caregiving Excellence supports and empowers caregivers and care providers, advances the knowledge and capacity of the caregiving field, and advocates for effective and visionary social policy, with a disability-informed approach.



Our Areas of Focus

- Education and Leadership Development
- Support Networks and Knowledge Sharing
- Advocacy and Policy Development
- Inclusion and Underserved Communities









We are on break!

Please return at 12:15 PM EDT

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Integrating Caregivers to the Healthcare Team



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Global Voices of Caregiving





I am Nelly.

I am from Taiwan.



















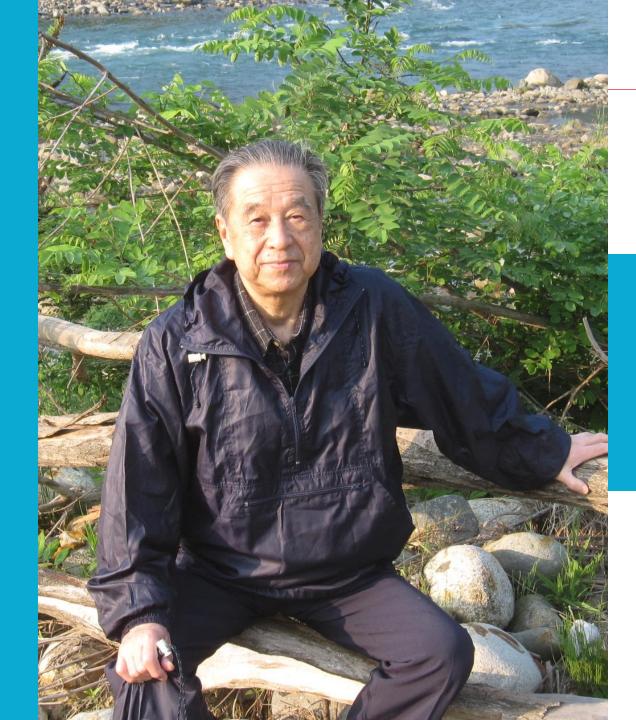




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Global Voices of Caregiving

Mr. Terashima | Japan





I am Mr. Terashima.
I am from Japan.





Mr. Terashima | Japan

My wife and I are both age 84 now and will celebrate the 60th anniversary of marriage next year. It has been 5 years since I felt something wrong to my wife. She was diagnosed with Alzheimer's Disease. She is bedridden now.





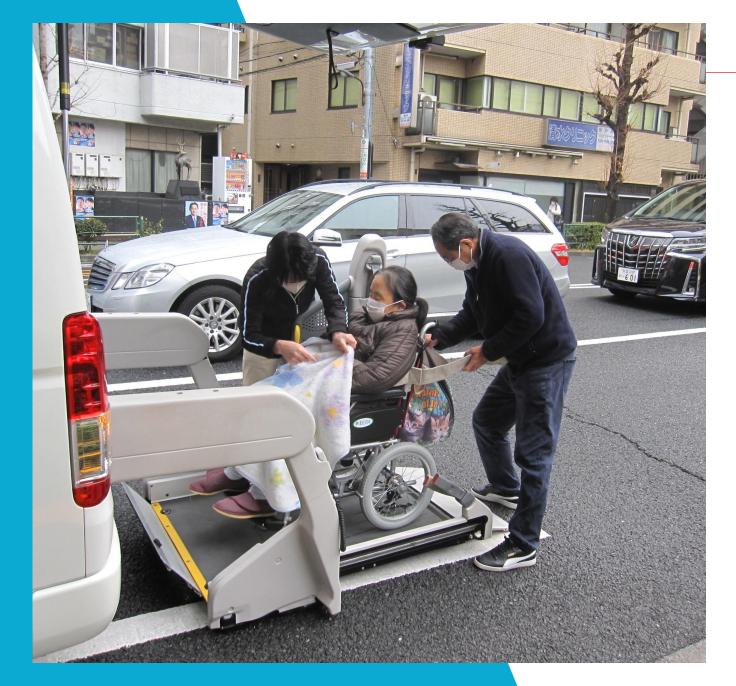


Mr. Terashima | Japan

Now, my wife is difficult to walk and uses wheelchair when she goes out. I felt that our life turns to the stable stage, because I become to be able to understand her feeling and emotions and she also understands my feelings and acts obediently.







Mr. Terashima | Japan

We thank all staff of day service center and short stay service for supporting us six days a week, even under the situation COVID-19 variants are prevalent everywhere. I am grateful every day. Thanks to you, I have been able to relieve my own stress and preserve my physical and mental strength. I will continue to care for my wife, so-called "Rou-rou Kaigo (elderly care by the elderly)," although I am not sure how long I can continue.



Developing Young Carer Education, Support, and Training in South Africa



2022 World Carers Conversation

Franclo Henning, MBChB; FC Neurol (SA); PhD Associate Professor, Consultant Neurologist Department of Medicine Stellenbosch University Melinda S. Kavanaugh PhD, MSW, LCSW Professor, social work

Helen Bader School of Social Welfare University of Wisconsin - Milwaukee





Overview

ALS/MND in South Africa Young caregivers in South Africa SA Pilot study data YCare program Adapting to SA culture Next steps

Amyotrophic Lateral Sclerosis (ALS) – symptoms and the need for care

average 2 to 5 years from onset

Average age between 40 and 70 – increasing earlier age of onset

Loss of muscle movement

Need for daily caregiving – primarily from family.

intensity of symptoms, complicated and costly equipment, expensive and detailed medication regimen, and heavy lifting and transferring.

family caregivers often provide physical care, manage devices, and attend to safety needs, among other tasks.

ORIGINAL ARTICLE

Incidence of motor neuron disease/amyotrophic lateral sclerosis in South Africa: a 4-year prospective study

F. Henning* (D. J. M. Heckmann*, K. Naidu*, L. Vlok*, H. M. Cross* and B. Marin*

"Division of Neurology, Department of Medicine, Faculty of Medicine and Health Sciences, Stellenbosch University, Cape Town;

Division of Neurology, Department of Medicine, Faculty of Health Sciences, University of Cape Town, Cape Town, South Africa; and

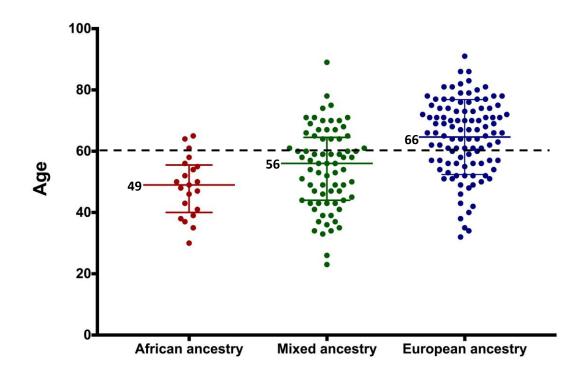
"Ministere de la Sante et des Solidarites, Cellule Interministérielle Recherche MSS/MES II., Paris, France

ALS/MND in South Africa

- Incidence in SA is lower than in USA and Europe (because of a lower incidence rate in the non-European/non-white population groups),
- YET age of onset in these groups is 10-15 years earlier
- Therefore, higher proportion of people with ALS with young children in the household.
- These are also the socio-economically disadvantaged population groups, putting an even greater burden of care on the family members (unable to afford assistance).
- This affects the education of these children, and the poor are already left behind by the education system

RESULTS (3)

- Median age at diagnosis (p < 0.0001)
- Young-onset ALS (<45):
 - 33% of black African
 - 26% of mixed ancestry
 - 7% of white



Children and youth caregivers in ALS: Data from a U.S.

study



US data on children and youth caregivers in amyotrophic lateral sclerosis

Melinda S. Kavanaugh, PhD, Chi C. Cho, MA, Megan Howard, MA, Dominic Fee, MD, and Paul E. Barkhaus, MD

Neurology® 2020;94:1-8. doi:10.1212/WNL.00000000009217

Correspondence Dr. Kavanaugh kavanaug@uwm.edu

- •Almost 50% were younger than 12 years old
- •The majority were female, but many males participate in care
- •Care occurs weekly often daily for many hours per day
- •Young caregivers often provide care alongside another adult in the home or family
- •All youth felt they had *some* responsibility for care, while 24 (44%) felt they had *a lot* of responsibility for care.

Outside the U.S. – little is known about young carers in ALS, including under resourced areas such as South Africa

South Africa young carers



- Young carers and youth headed households
- South Africa targets young carers in HIV/AIDS (See Cluver et al, 2009, 2012)
- Policies and programs targeting education about HIV/AIDS in young carers
- Support networks, economic development, sex education, and life skills programs for youth orphaned by HIV/AIDS

No previous data on young carers in ALS/MND, or other complicated neurological disorders – despite the potential for intense, daily care

South Africa Project overview

Started in 2016 – Funded by the International Alliance of ALS/MND and the ALS Association

PROJECT AIMS

- Describe ALS caregiving and living with ALS
- Detail care needs and supports for young carers
- Inform development of support programs and education for ALS families in South Africa

Full project team:

- Stellenbosch University department of Neurology
 - Dr. Henning
- MNDA South Africa
 - Care coordinators
- Chris Hani Baragwaneth Johannesburg
 - Dr. Mochan and Dr. Smith
- University of Wisconsin Milwaukee
 - Helen Bader School
 - Melinda Kavanaugh and Miranda Wenzlaff
- Stellenbosch University
 - School of social work













South Africa Data collection

- Family interviews
 - Patients with ALS/MND
 - Youth 8-18
- Interviews lasts 30-45 minutes
- Met in homes and in clinics
- A total of 20 families in both the Cape Town and Johannesburg participated.



Pilot data

Adult

N = 20

- Male 17; Female 3
- Age range from 34 67
- Education level
 - One participant past high school
- Race/ethnicity
 - Black 6
 - White 5
 - Colored 7
 - Other 2

VULNERABLE CHILDREN AND YOUTH STUDIES https://doi.org/10.1080/17450128.2020.1837409





Young carers and ALS/MND: exploratory data from families in South Africa

Melinda S. Kavanaugha, Francio Henning ob and Andre Mochan

^aSocial Work, Helen Bader School of Social Welfare, University of Wisconsin-Milwaukee, Milwaukee, WI, USA; ^bConsultant Neurologist and Lecturer, Division of Neurology, Department of Medicine, Faculty of Medicine and Health Sciences, Stellenbosch University, Cape Town, South Africa; ^cNeurosciences, University of the Witwatersrand, Johannesburg, South Africa

Youth

N = 20

- Male 11; Female 9
- Age range 9 20
- CG tasks
 - Dressing and undressing parent
 = 15
 - Administer medications = 14*
 - Toilet parent = 10
 - Bathing parent = 7
 - Feed parent = 12

ALS skills, knowledge, and support

- Youth spend an average of 24 hours per week providing care
- Feel overwhelmed majority requested assistance with hands on care
- Both adults and youth stated a need for more assistance from the association and others.
 - Equipment
 - transportation assistance
 - financial help
- Patients acknowledge intensity of youth caregiving, yet had no other choice due to isolation, financial limitations and few supports.
- Youth felt a *strong sense of responsibility for care*, even when it impacted school and their own well being.

65% of youth never received any training or guidance about caregiving

Why Focus on Caregiver Skills and Training?

Attention to the caregiving experience is vital to patient quality of life and caregiver well-being

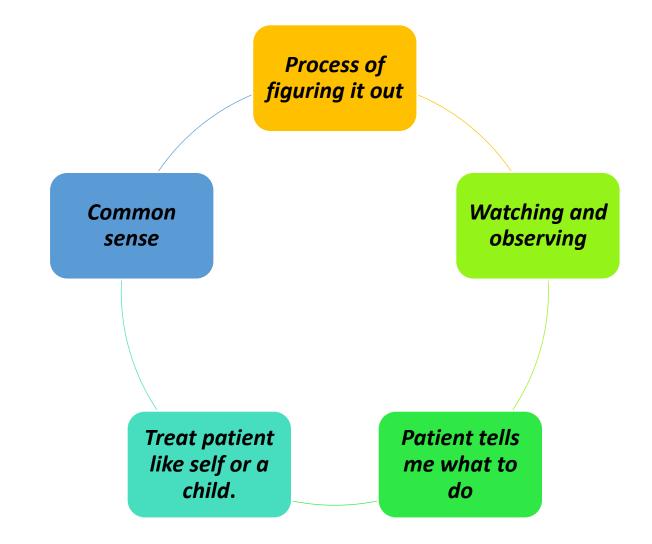
Skill-oriented training programs have been shown to improve well-being and reduce anxiety and depression in adult caregivers

The inclusion of *support* in these programs is critical

Yet all caregiving programs target the adult caregiver, missing a large portion of family members who provide care......

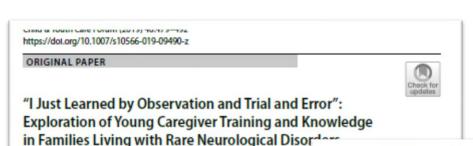
How young carers know what to do?
Results from U.S. data

(Kavanaugh, Howard and Cho, 2018)



To address the lack of education, care skills and support, we developed YCare

YCare is an evidence-based, modular, professional-led, training, education and support program for young carers





Melinda S. Kavanaugh^{1,2} · Chi C. Cho² · Megan Howard¹

Feasibility of a multidisciplinary caregiving training protocol for young caregivers in families with ALS

Melinda S. Kavanaugh, Megan Howard & Lori Banker-Horner

To cite this article: Melinda S. Kavanaugh, Megan Howard & Lori Banker-Horner (2018) Feasibility of a multidisciplinary caregiving training protocol for young caregivers in families with ALS, Social

Neurodegenerative Disease Management Disease Management

Research Article

For reprint orders, please contact: reprints@futuremedicine.com

Skill, confidence and support: conceptual elements of a child/youth caregiver training program in amyotrophic lateral sclerosis – the YCare protocol

Melinda S Kavanaugh*, 10, Young Cho², Dominic Fee³ & Paul E Barkhaus³

1 Helen Bader School of Social Welfare, University of Wisconsin-Milwaukee, PO Box 786, Milwaukee, WI 53201, USA

2 Joseph J Zilber School of Public Health, University of Wisconsin-Milwaukee, Milwaukee, WI 53201, USA

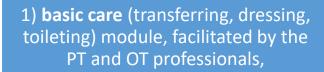
2 Department of Neurology, Medical College of Wisconsin, Milwaukee, WI 53226, USA

3 Latter for correspondence Tol. 3 Lat 2 79 4414: Kayanaun@hummerki

Tested in 11 sites across the U.S.













3) assistive devices (communication and power chair) module, facilitated by respiratory and assistive technology specialists.





Training provided by ALS professionals – PT, OT, SLP, Respiratory, social work and neurology



Group enters the rooms – all materials are set on tables, floor etc.



Participants can touch anything – all open to let them look and see what is in the room

Module breakdown



Start by asking what they know and what they currently do. This is the flexibility and will guide the session.



Start with each task (no more than 3-4) – begin teach back process ending with youth teaching back to tasks to you



At the end of the module - ask what they learned - write on the large post it

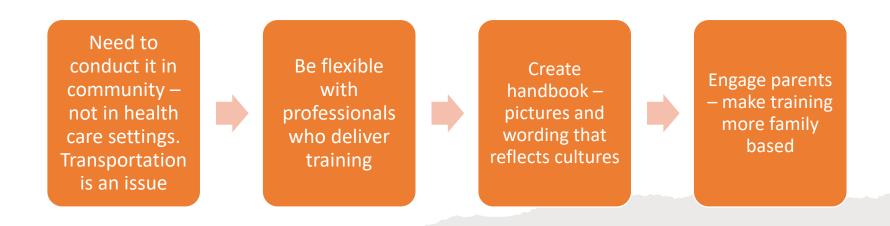
Program <u>assumptions</u> based on U.S. context

- Access to a variety of allied health professionals
- DME equipment available to all living with ALS

What do we need to know to adapt to South African context...

- Availability of Allied Health professionals
- Few, if any, DME available for those living with ALS/MND
- Culture is everything as is spirituality

Met with families and health care providers to assess how we can adapt YCare to South African Context.....



Start by creating a manual for youth

Full collaborative effort

- MNDA
- Neurologists
- Care coordinators
- Physiotherapists
- Social workers

We took the manual we created for the U.S. context, and adapted all sections



How do patients and their families find support?

Motor Neurone Disease Association (MNDA)

Once someone is diagnosed, they can be referred to the MMDA, who sends advisors to the patient's home to do an assessment. The advisor can explain the disease and the way forward. MMDA of South Africa offers the service of counseling patients and family, loaning out equipment, and holding support groups.





Palliative and Spiritual Care

Palliative (end of life) workers and spiritual care workers are a big part of the care teams for patients with MMD. Patients and families may fear that being ick means that they are "cursed", or they may feel they are being "punished" or "abandoned" by a higher power. Having a care team that combines both religious and traditional customs and beliefs can help families better deal with the disease.

Famil

Family is an important source of support for patients with MND. Family members can help people with MND with basic care needs, help them get around, and help with tasks that are hard to do because of MND. Family can also provide emotional support, but by spending time with them and talking with them about how they feel. People with MND often rely most on family members to help them with daily life. Family can also talk to each other about how they feel when things start to feel difficult.



Communit

Sometimes patients and families feel shame or feel like they are no longer accepted by the community after being diagnosed with MND. However, there are groups that help with care and offer services to help you. Church community groups can also be more accepting to families in need.

Persona

- 1. What are some ways that YOU find support?
- 2. How do you talk to your friends about caring for someone with MND?
- 3. Who do you talk to when you need help?

Now that we know who everyone is – let's get to the training!



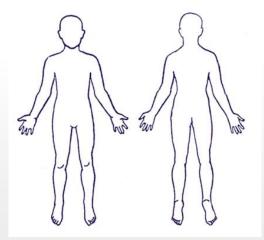
This handbook will guide you through each station throughout the day.



We hope all youth will join in on the training activities today. Even if you haven't done something as part of care before, you may need to in the future and having the correct training is still important.

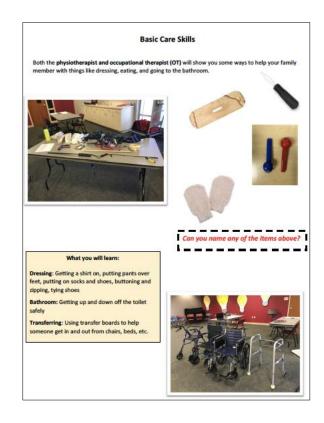
So far, we've learned a LOT about MND. We know that MND affects everyone differently.

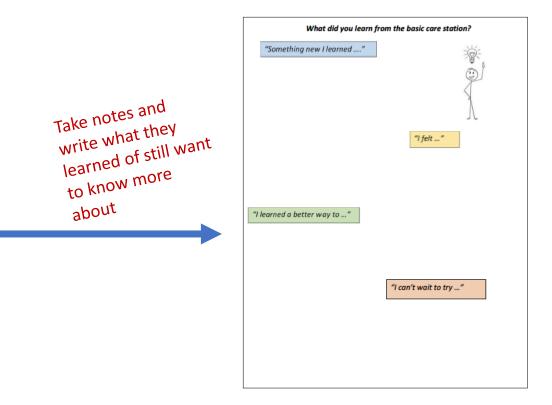
Where is your family member affected by MND? (Circle or color the areas below).



Basic care skills

- Transferring
- Dressing
- In the absence of many specific tools, training uses household items





Communication and feeding

- Focus on low tech easy access, paper/pen, markers, boards
- Devices at home cups to cut for nose, easy swallow, make handles heavy with wrap



Assistive Devices

At this station, you will see some of the tools or 'assistive devices' your family member may use. The speech therapists will show you how to use them and you can even test them out yourself!

Touch screens and eye gaze devices help

people with MND communicate. These

devices help people share their feelings.

The devices also help them to share their "story" with others.

Different tools can help family members do things for themselves.

around. You'll learn how to use and assist

someone who uses a wheelchair.

Sotolk 32 Express



Have you ever used a Tobli eye















Above: Universal cuff, non-slip matting, and adaptive knives (reflex slicing knife)



The occupational therapist will show you ways to help your family member eat.

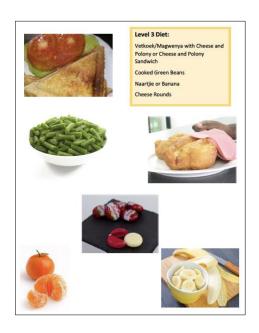
- You will learn what happens when muscles it the mouth and throat do not work well.
- How to change food textures:
- o Less chewing
- o Small bites o Avoid crumbly/chewy/crunchy foods
- Ways to help with feeding:
- o Go slowly, give small bites and sips of
- Use special cups and straws
- o Use a small sponge to check for food between cheek and gums

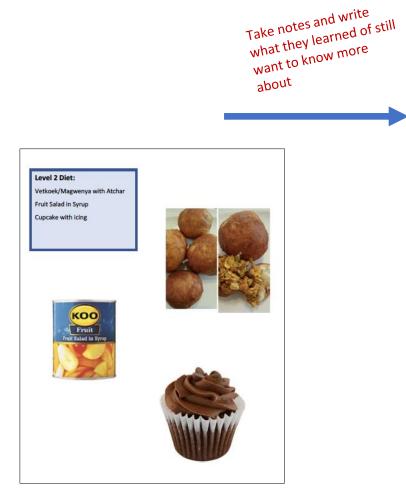


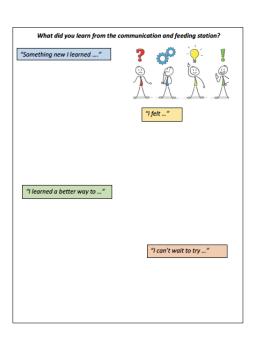
with bendy straws, and a plate guard

Food texture and swallowing

- Focus on culturally specific and available foods
- Understand the varying textures and thickness







Respiratory

- Breathing and cocking difficulties are common with ALS/MND
- Devices assist with breathing and airflow

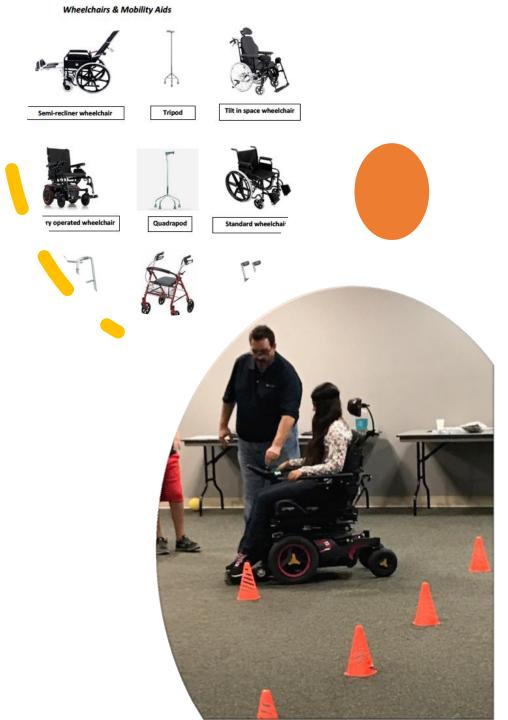




Youth can test them out – see what it is like to use one!

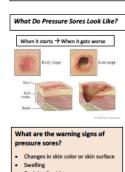
Assistive devices

 Focus on wheelchairs, transferring and making comfortable in seats

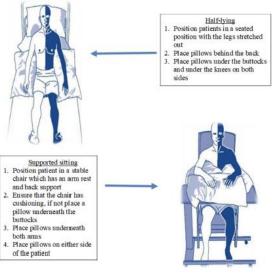


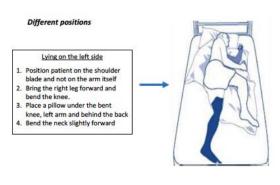


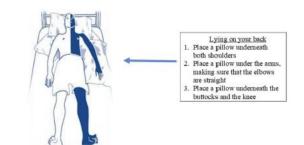
MND can make it hard for patients to move around on their own. When this happens, a pressure wound (a sore or injury on the skin) can form on their body. This is sometimes called a bed sore, and there are ways you can help stop these from happening.





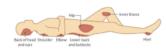






- Draining liquids
- Skin that feels cooler or warmer to the touch than other areas
- Tender or painful areas

- What You Will Learn: Why you should position correctly: o Help stop bed sores or pressure sores from forming
- o Give patient comfort and support
- o Stop the muscles from getting tight Keep muscles from overstretching
- How to prevent pressure sores
- o Provide good skin and pressure care
- o Help patients with MND change their
- o Skin creams can help: Prep shaving cream, baby bum
- o Change position every 2 hours when lying
- Different positions for people with MND
 - o MND patients may find it hard to breathe when lying flat
 - o Find ways that make it easier to breathe o The best position is usually sitting up or slightly reclined (leaning back), with the head and neck supported



PRESSURE SORES

IMPORTANT!!!

MAKE SURE TO CHANGE POSITIONS ON A REGULAR BASIS CHANGE POSITIONS EVERY 1-2 HOURS

Pressure care

Given the lack of mobility and often difficulty accessing wheelchairs and power chairs, persons with ALS are often laying down for hours/days on end. Thus, pressure sores are a major issue in SA

Meeting new friends and accessing support

HERE

TO

HELP

Community Resources

cnr. 4th St. and 6th Ave.

SA (South African Social Security Agency) (Grants & food parcels)

501 Prodinsa Building

012 400 2322 (Switchboard) 0800 60 10 11 (Grant Enquiries)

Family Worship Centre (Westbury hospice)

Corner Harmony and Retief Street, Hursthill Johannesburg, 2093

(011) 837-2999 info@fwchospice.org.za https://fwchospice.org.za/about-us/

MND Association of South Africa

0215316130 & 0215316131 mndaofsa@global.co.za

eila.mnda@global.co.za (0723264477) http://mnda.org.za/

Other Resources Police: 10111

Childline Gauteng: 08000 55 555

The South African Depression and Anxiety Group (SADAG): 011 234 4837 Lifeline South Africa — Counseling Phone Number: 0861 322 322 Any emergency (from a mobile phone): 112

Netcare 911 (life-threatening emergencies): 082911

Police Flying Squad: 10111



A big part of this day is the chance to meet other children who have a family member with MND!

You can talk about what it is like to live in a family with MND or how it feels to do things to help care for a family member. Best of all - you can make new friends.

- You are not alone.
- o There are children like you all over South Africa and all over the world.
- You can talk to other children like you who have a family member with
- You can share stories and learn from each other
- o You can ask how others deal with MND, caregiving, and the loss of a family member.
- By talking with the social worker and other youth, you can find ways to make caregiving less stressful.





What things would you talk about with other youth like you who have a family member with MND?

- Major aspect of YCare is developing new peer groups – reducing social isolation
- Also providing access to local ALS/MND support

Focus on care, and how they feel about being a caregiver

Dealing with caregiving...



This section is for you. A place to write down how it feels to help provide care for a family member with MND. This can be any feeling you have – just for you. Sometimes it helps to write things down.

Taking care of someone else can be hard. It can make us feel a lot of different ways. Sometimes we need to find ways to 'deal' with those feelings and take care of ourselves. What are things that you do to take care of yourself? How do you make yourself feel better when you feel mad or sad?

By taking care of yourself, you are also able to help take care of your family member. What things can you do to help you feel better, or deal with your feelings about being a caregiver?

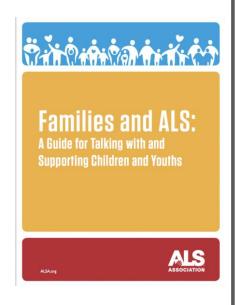
We hope that you feel more comfortable and a little less worried about the care you provide your family member with MND. Working with Stellenbosch and Witwatersrand to train health care staff

Families participate in several sessions in both Cape Town and Johannesburg this summer

Continue adaptation to include an adult training session as well, given the lack of any care skill and training for all caregivers

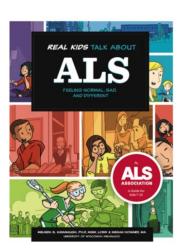
Currently translating the manual into Zulu, Afrikaans, and Tswana

Next steps









Printed Resources for young carers

Available in French, Dutch, Italian, German and English (soon to be in Spanish)

Thank you

- Families across South Africa who have participated in our project
- Research and development partners:
 - Witwatersrand Neurology
 - Andre Mochan
 - Hayley Hoch
 - Samira Haffejee
 - UWM
 - Miranda Wenzlaff
 - MNDA
 - Sheila Kendall
 - Wendy Toerie
 - Witwatersrand Social Work
 - Thobeka Nkomo
 - Busisiwe Nkala-Dlamini
 - Motlalepule Nathane-Taulela

Please reach out happy to answer any questions!!





Ycare website: https://uwm.edu/ycare/

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Global Voices of Caregiving

Marcelo | Brazil



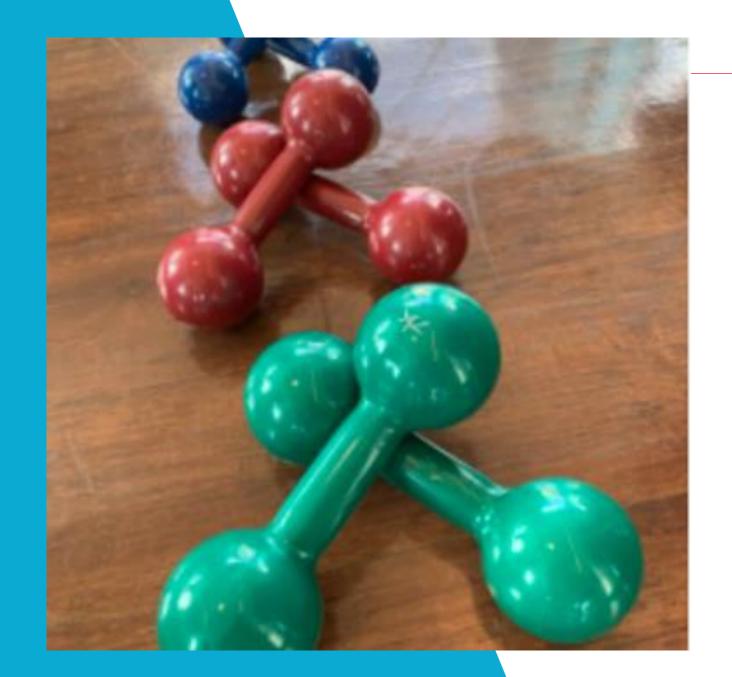


I am Marcelo. I am from Brazil.

Hi! How are you all? My name is Marcelo, I am a Brazilian and I live in Brasília, the country's capital. I have been a caregiver for more than 7 years for Claudia Lopes, my wife.







Marcelo | Brazil

In the photos, I try to show that it works very well for every caregiver to stay active, because it brings gains both for the body and for the soul. Even if the role of caregiver presents you with daily challenges, which is common, I believe that you need to seek some outlet to support the emotional wear and tear on your own health. Stay aware, keep taking care [of your loved one] while taking care of yourself!







Marcelo | Brazil

For this to improve, caregivers need to know the benefits of physical activity to improve quality of life, reduce stress and develop body awareness.

One suggestion is to look for pleasurable activities that bring change to the way you look at the perspective of life from now on, with more hope, more optimism, more faith. This is the way!







Marcelo | Brazil

In my vision for a world that includes and supports caregivers, we would need to receive quality information about the benefits of practicing physical activity and the impact of this change in attitude on our self-esteem, concentration, and relationship with the patient.

I am dedicated and happy taking care of myself and taking care of my wife! Are you taking care of yourself? Let's do it! Let's move!





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Caregiver TLC

Implementation and Assessment of a Virtual Psychoeducational Intervention for Informal Caregivers of Older Adults with Chronic Illness in North Carolina, (USA)

#WCC22 #worldcarers

Disclosure



We would like to acknowledge and thank Southminster for the funding this program and their continued dedication to supporting healthy aging initiatives.

All presenters have no actual or potential conflict of interest to declare in relation to this presentation.

Research Team





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- Katie Cooper, MSW, Memory and Movement, Charlotte



Advisory Board

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- · Hiep Pham, MD, Charlotte NC



This work was supported by Southminster Community Fund.



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Introduction

Dolores Gallagher Thompson, PhD, ABPP

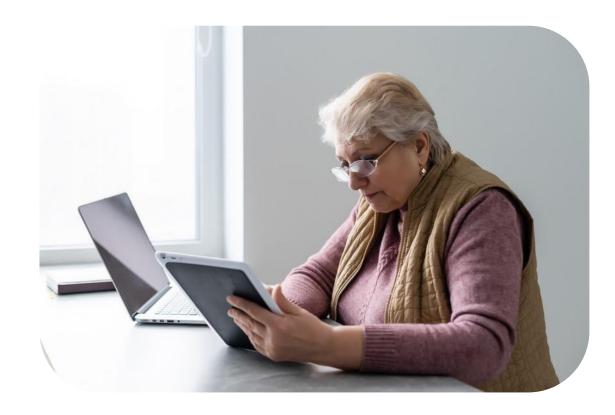
Caregiver Research and Technology



In the past decade, there has been a strong push to advance intervention research focusing on programs that better support the needs of family caregivers at all levels

A priority topic: Technology (in all its forms) and how best to utilize it

- Benefits of technology include¹:
 - Access to information, education, & training
 - Can be a vehicle to reduce social isolation
 - Supports caregivers who find it difficult to access care - either due to geographic isolation, role demands, or other factors that limit the ability to participate in in-person programs

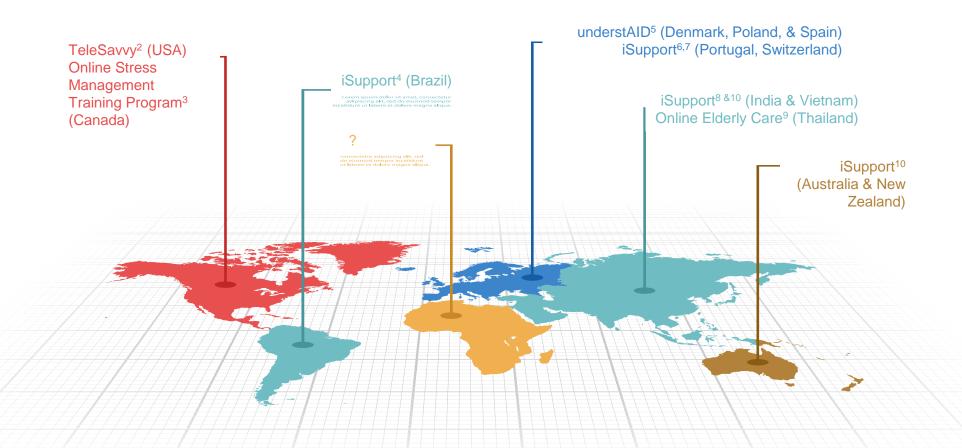


International Use of Tech in Psychoeducational Programs



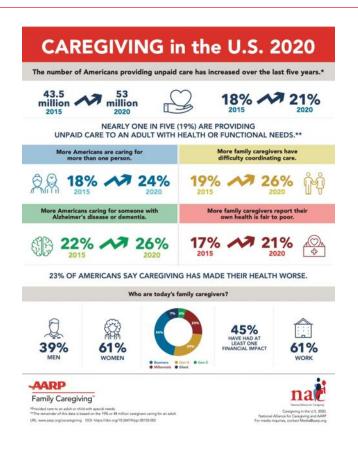
Many evidence-based programs are now available; they need adaptation for global use

- Cultural adaptation is a necessary first step
- Often conceptual translations are needed, depending on the situation
- iSupport for Dementia Program website: https://www.who.int/publications/i/item/9789241515863



Who are Caregivers?





Unpaid caregivers are the vital to the functioning of our healthcare system

Benefits of involving caregivers in care decisions:

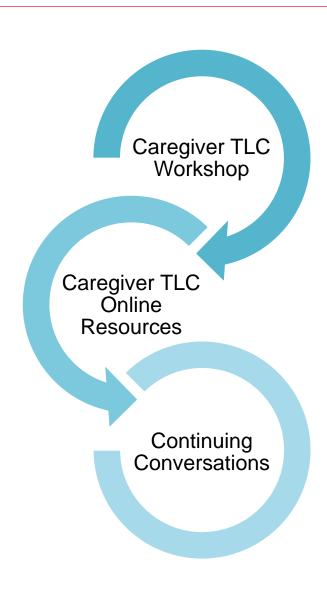
- Improves patients' access to services & reduces their unmet needs^{11, 12}
- Better quality of care & increased safety^{13, 14, 15}
- Improved quality of life for care recipients^{12, 13}
- Can delay patient institutionalization^{12, 16}
- Cost savings through lower rates of healthcare utilization & reduced readmission rates¹⁷

But these benefits come at a high cost to the caregivers themselves¹⁸

- 21% Caregivers report fair to poor health
- 23% report caregiving has made their health worse
- 36% report high emotional stress; several studies found 50% with depressive symptoms

Caregiver TLC Study Description





Caregiver TLC consists of three parts

- Workshop: held over Zoom / 6 weekly sessions
- Online Resources: workshop materials, videos, and curated resources
- Webinar: monthly, on-line webinar/ discussion

Goals

- reduce self-reported stress and depression
- improve management of their care plan for the carerecipient
- foster resilience on a larger scale by promoting Virtual Communities of caregivers.

Technology



- Technology Used in this Study
 - Online surveys for registration, consent, assessments
 - Workshop and Webinar use the HIPAA-compliant teleconferencing platform Zoom
 - Access to the website through desktop computer, laptop, or smart phone



Benefits

Less travel time for caregiver
Less exposure to possible health risks
Can join from convenient setting
May be more comfortable sharing personal
Information (greater anonymity)



Barriers

Digital Divide

Lack of knowledge re how to use technology

Embarrassment re home/ background/ setting

Interruptions from care recipient/ others

Difficulty seeing/ hearing/downloading info

Community/University Partnership





Due to concern over the pandemic and its isolating effects on caregivers, a partnership was formed between the community-based organization, Southminster, and UNCC to offer a psychoeducational program, Caregiver TLC. The program focuses on caregivers and provides them with the skills and tools they need to combat isolation and to improve their quality of life.

"We view this investment of our charitable resources as an effective way to create solutions to support caregivers, which we know ultimately will improve not only their well-being, but those they are caring for."
-Ben Gilchrist, Southminster
President/CEO

Aims of this Research



Offer online evidence-based psychoeducational programming to diverse caregivers

Foster resilience via cost-effective support for caregivers at the community level

- Virtual communities
- Easy access online resources via website (https://caregivertlc.org/)
- Train local aging and health professionals in the delivery of the program
 - Jewish Family Services of Greater Charlotte
 - Memory & Movement Charlotte
 - The Ivey
- Embed Caregiver TLC in community organizations





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The Intervention

Ann Choryan Bilbrey, PhD



Thrive Learn Connect Three Part Intervention



- Primary
 - required six session psychoeducational workshop held over Zoom
- Auxiliary Options
 - access to a website with extensive resources available to them
 - Workshop session summary
 - Materials: Participant Guide, PDF of slide set, Handouts, Make Up Videos, Resources sort by session topic, Continuing Conversation videos
 - ongoing monthly interactive 90 min meeting
 - 45 min webinar on topic
 - 45 min interactive discussion





Caregiver TLC Workshop



Session Components:

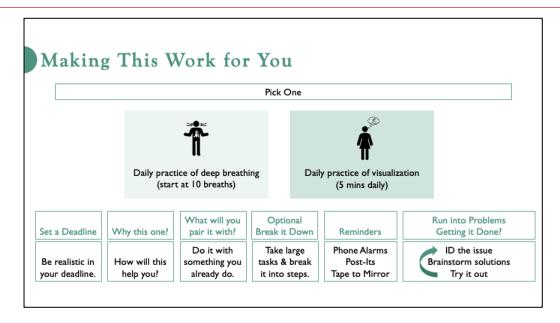
Start with Deep Breathing, Check In, Agenda, Session Content, Take Away, Action Plan

Sessions:

- Strategies for Stress
 - Topic: Stress Skills: Recognition of Stress Signs, Deep Breathing, Visualization
- Dealing with the Blues
 - Topic: Depressive Symptoms Skills: Behavioral Activation (Positive Activities)
- Bouncing Back
 - Topic: Resilience Skills: Balanced Worldview (finding the positive), Altas CareMap (care network)
- Filling the Well
 - Topic: Self-Care Skills: Finding small self care things to do, Sleep Hygiene, Cognitive Barriers
- Coping with Frustration
 - Topic: Anger Skills: Using Physical Signs and Thoughts to Identify Emotion, S.T.O.P Technique
- All by Myself
 - Topic: Social Connectedness & Workshop Review Skills: Various ways to stay connected via online means

Integration of New Skills: Action Plan & Check In



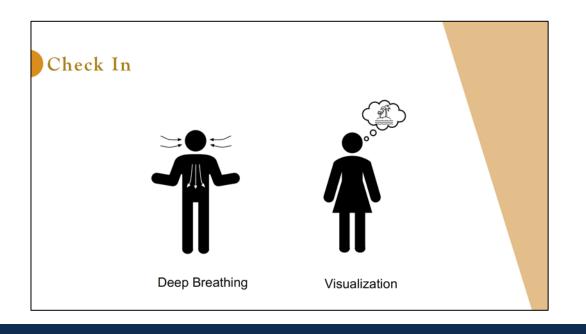


Action Plan

- Built using SMART Goals
- Aim is to teach the process of goal setting and overcoming barriers
- Participants are encouraged to write it down as the facilitator leads this discussion
- Participants are encouraged to share their goals, identify possible barriers and plans to deal it them

Check In

- Done at the start of the next session
- Interactive discussion with heavy participant engagement
- Review barriers and successes
- Focus is on what was learned from experience did the skill work? Were modifications needed?

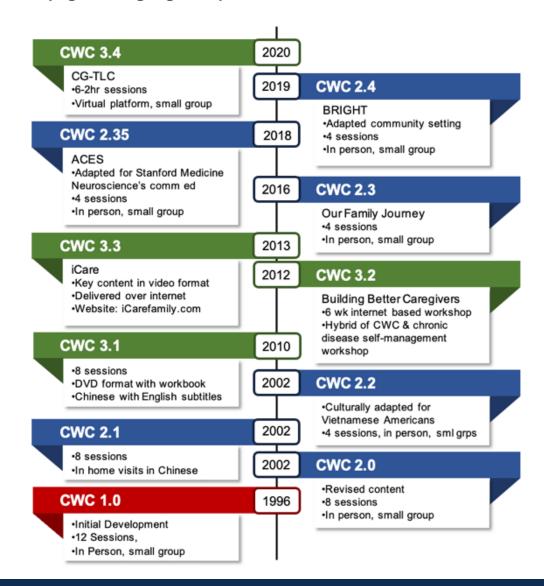


Research base



Caregiver TLC was sourced from Coping with Caregiving

Coping with Caregiving Development Timeline





Fidelity

1. Design of Workshop

2. Training

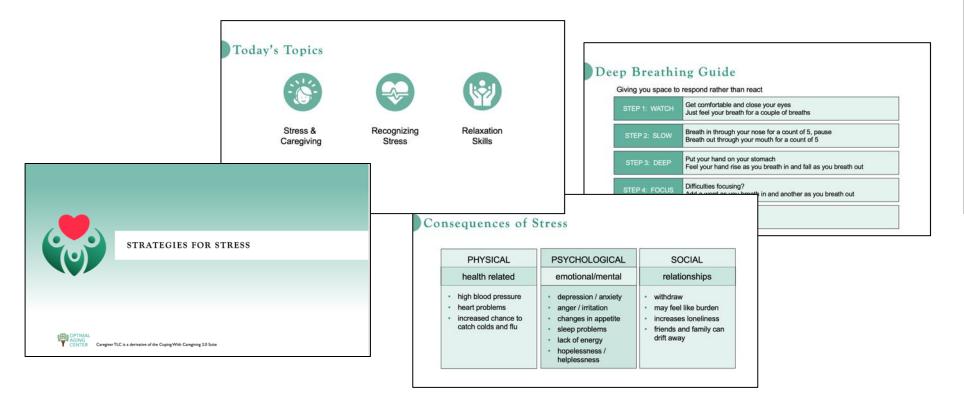
3. Observation

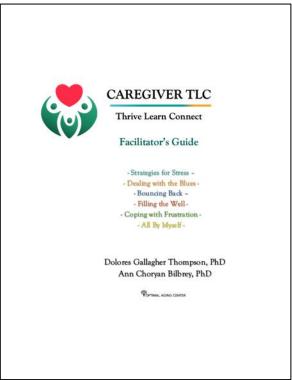
4. Weekly Facilitator Meetings

1. Design of the Workshop



- Manualized
- Power Points guide delivery of important information and teaching of skills





2. Training



- All Training is done virtually over the Zoom platform
 - We have completed two facilitator trainings and are in the process of a third training

Training covers:

- Psychoeducational Content
- Facilitating engagement and group participation
- Importance of fidelity in research

Learning Virtually

- Synchronous: Each training cohorts has six 2hr sessions with developers/trainers
- Asynchronous: Viewing of prerecorded Workshop, facilitator online access to content materials, including power points, facilitator guide, handouts, along with access to all materials available to the participant

3. Session Observation



- First time facilitator runs a workshop
 - All six sessions are observed and scored
- Each additional time a facilitator runs a workshop
 - Random session chosen to be observed and scored
- Each session has both common (A, B, F, & G) as well as unique skills to be covered (C – E)

CG-TLC Fidelity

Observer

Facilitator Name

Session Name

Strategies for Stress Dealing with the Blues Bouncing Back Filling the Well Coping with Frustration All by Myself

Date of Session (

ontent

- A. Check In
 - 0. Facilitator did not do check in
 - 1. Facilitator started to do check-in and attempted to engage Caregivers but only minimally
 - 2. Facilitator engaged most Caregivers: reviewed previous action plans & did problem
 - Facilitator fully engaged the participants and reviewed previous' weeks action plans including both successes and difficulties and helped Caregivers to problem solve barriers.
 - n/a

B. Today's Topic

- 0. Facilitator did not cover the agenda session lacked focus & structure
- Facilitator made reference to the agenda at the beginning but did not follow it went "off topic" several times during the session
- Facilitator followed the agenda as it was written stayed "on track" for most, if not all, of the session – minor deviations noted
- 3. Facilitator covered all points on the agenda & stayed "on track" virtually the whole time

Session One: Strategies for Stress

- C. Topic I Stress & Caregiving (CG Specific info, Stress Intro, Consequences)
 - 0. Facilitator covered most of the topics but left out / skipped over some material
 - Facilitator lectured to Caregivers covered the material, but failed to engage Caregivers in discussion.
 - Facilitator explained material & engaged Caregivers in discussion to some extent interaction occurred but more time was spent (relatively speaking) explaining than discussion
 - Facilitator fully engaged the Caregivers: explained the material, provided examples, encouraged all Caregivers to respond, answered questions, and provided a strong interactive experience
- D. Topic II Recognizing Stress (Stress Signs, Mapping Stress)
 - 0. Facilitator covered most of the topics but left out / skipped over some material

- Facilitator lectured to Caregivers covered the material, but failed to engage Caregivers in discussion
- Facilitator explained material & engaged Caregivers in discussion to some extent interaction occurred but more time was spent (relatively speaking) explaining than discussing
- Facilitator fully engaged the Caregivers: explained the material, provided examples, encouraged all Caregivers to respond, answered questions, and provided a strong interactive experience.
- E. Topic III Relaxation Skills (Intro, Deep Breathing, Intro, Visualization)
 - 0. Facilitator covered most of the topics but left out / skipped over some material
 - Facilitator lectured to Caregivers covered the material, but failed to engage Caregivers in discussion
 - Facilitator explained material & engaged Caregivers in discussion to some extent interaction occurred but more time was spent (relatively speaking) explaining than discussing
 - Facilitator fully engaged the Caregivers: explained the material, provided examples, encouraged all Caregivers to respond, answered questions, and provided a strong interactive experience

F. Take Away

- 0. Facilitator did not cover the material got distracted & did not return to planned topic
- 1. Facilitator lectured about Take Away but failed to engage Caregivers
- 2. Facilitator engaged Caregivers to some extent but failed to offer all take away points
- Facilitator fully engaged Caregivers by having them provide summary and/or review the highlighted take away points.

G. Action Plan

- 0. Facilitator did not cover the material- got distracted & did not return to planned topic
- 1. Facilitator lectured about the Action Plan but failed to engage Caregivers in the practice
- Facilitator engaged some Caregivers in the practice exercise but did not respond well to questions or provide assistance to Caregivers who needed it
- Facilitator fully engaged the Caregivers by explaining the material, providing examples, answering all questions and checking in with each CG that he/she understood what to do

Did they mention continuing conversations? Yes/no Did they mention the website? Yes/no

STORY MAKE

Summary Statement

The Facilitator implemented the CG-TLC program

- 0. Not at all (0-5)
- 1. Poorly (6-10)
- 2. Well (11-15)
- 3. Very Well (16-21)



4. Weekly Facilitator Meetings



- Facilitators with active workshops meet weekly via Zoom
- Get questions answered about past or upcoming sessions
- If there were any issues or concerns raised during last session
 - What the issue / concern was
 - How was it handled
 - Was there any drift from the intervention intent
- Gather facilitator observations regarding content, caregiver reaction to content, overall engagement, and any other comments they wish to make.



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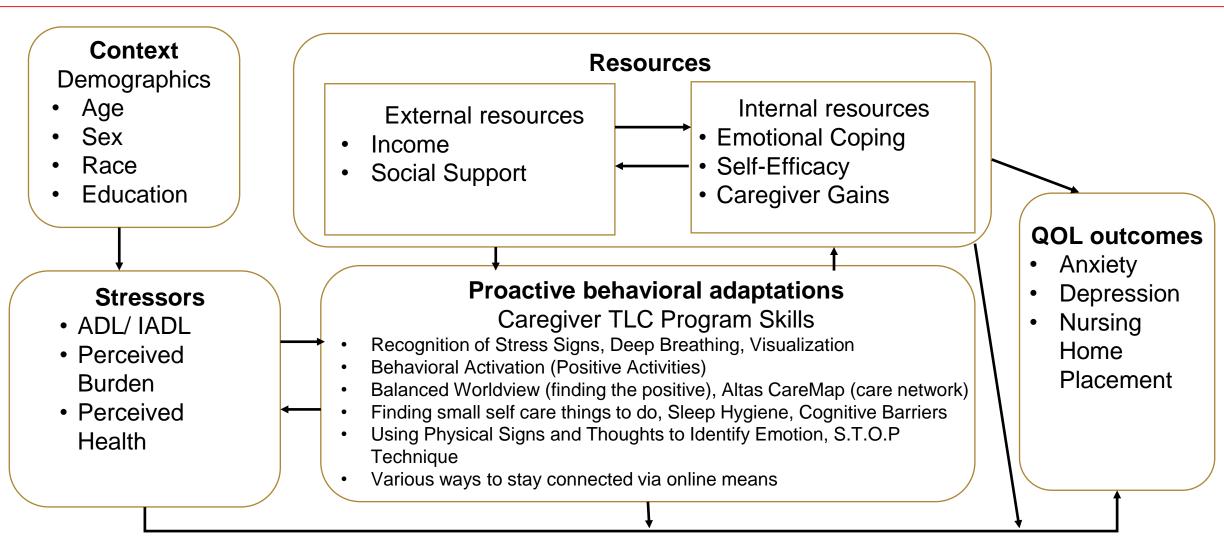
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Methodology

Jennifer Ramsey, PhD

Methodology: Conceptual Model

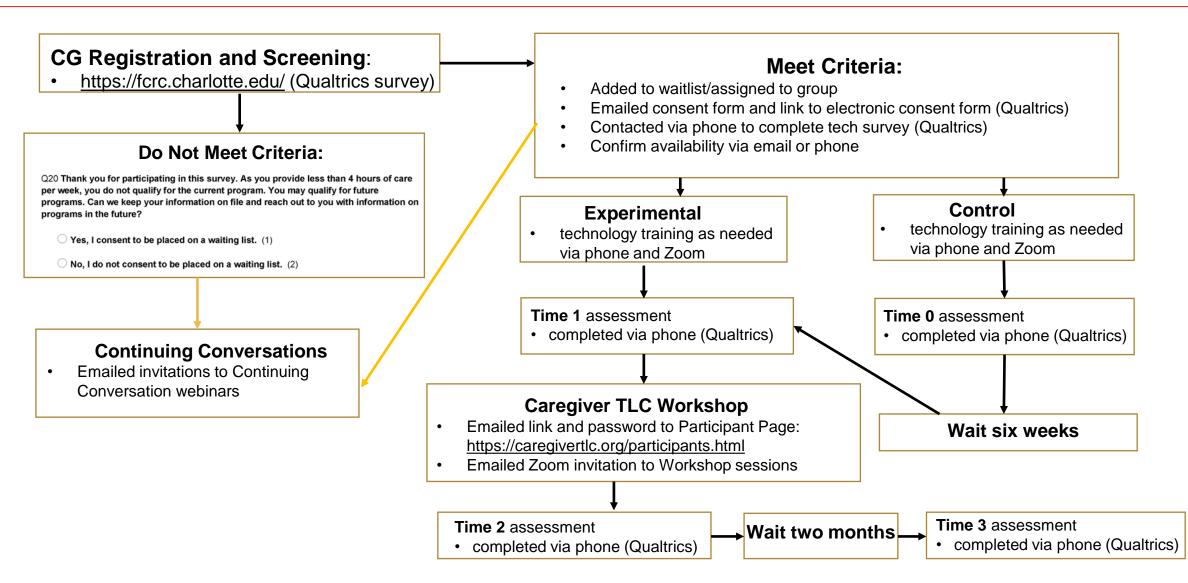




Conceptual Model showing potential predictors for caregiver outcomes adapted from ¹⁹Kahana, Kahana & Lee (2014).

Methodology: Participant Flow and Experimental Design





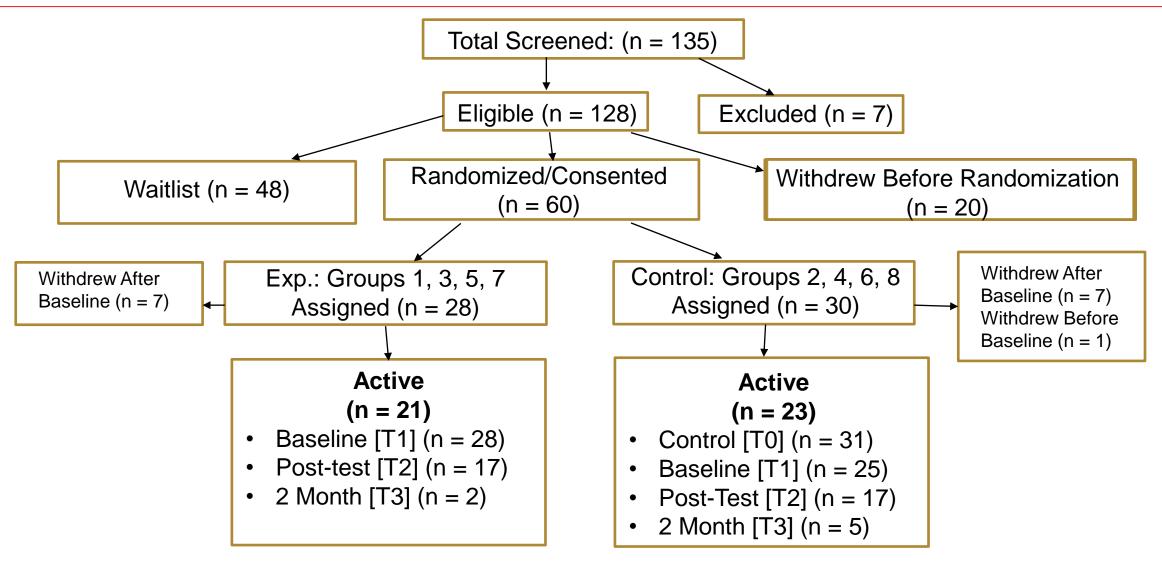
Addressing Digital Divide: Adoption and Use of Technology



- Technology assistance provided based on need
 - 91% of sample use computers daily
 - 2.2% of sample requested and received technology assistance

Recruitment, Eligibility and Randomization







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Engagement

Angela Burrow, CDP CADDCT

Workshop



"The most valuable part of the program for me was the unique CareMap we learned to use. It helped me see where our family had holes in our caregiving support and exactly who might be best to help us fill specific holes, such as identifying friends from church who could provide rides to church events. I also frequently rely on the breathing exercises and visualization we learned in one of the workshops to relieve stress," H.C., Caregiver

Online Resources



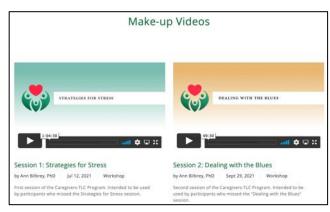
Welcome Page



Workshop Content



Session Videos



Online Resources



Continuing Conversation Videos



Continuing Conversations



Webinars

- Learning about "Triggers" & "Responses" & Ways to Modify Them
- Sharing Positive Activities Can Go A Long Way to Improving Mood!
- Communication Strategies for Avoiding Family Conflict
- Empowering Caregivers With a Voice: You Have a Voice... Use it!
- Forget what's lost, Focus on What Remains
- What We Need to Know About Dementia
- Caregiver Resources and Supports

"Thank you to you and your team for an extremely helpful ZOOM. I so appreciated the candid Q&A session. I now feel like I have a few places to start with my questions regarding Mom and Dad.", A.G. (caregiver)



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Future

Dolores Gallagher Thompson, PhD, ABPP

Embedding the Program in the Community



Create Master Trainers

- Train a Master Trainer for each community organization that wants it
 - Master Trainer has completed facilitator training and has facilitated 2 workshops successfully
 - These workshops are recorded and trainees are given extensive feedback re their ability to follow the protocol and handle emergent situations
 - They then Co-Train in the next training of facilitators

Collaborate with partner organizations

Embed Caregiver TLC Program in their regular services to clients

Sustain Continuing Conversations Webinar

 Dr. Montoro-Rodriguez will work with community organizations such as Dementia Friendly local initiatives, Senior Centers, PACE Program, Adult Day Care Centers, Memory Centers

Looking Back



What are two key things we would do differently?

Directly Address the Digital Divide to engage caregivers with limited experience: Institute for Local Self-Reliance/AARP *Exploring Digital Equity Fact Sheet Series*²⁰

This can take many forms – e.g, have program volunteers train caregivers in basics of the technology to be employed; work with local internet providers to increase service levels and/or bandwidth (at no cost to the caregiver)

Employ Community-Based Participatory Research Designs

- Greater insight into this community's specific regional needs
- Would give the community more of a sense of ownership which likely would extend into a wider adoption of the program once the research is completed
- More effective recruitment and retention of diverse populations

In Conclusion



Importance of caring for the caregiver

- Unpaid caregivers are the vital to the functioning of our healthcare system
- Policies need to be enacted on federal and state level to expand support services for Caregivers
- Appropriate care services reduce cost of care recipient care long-term¹⁷

Value of technology in caregiver research

- With technology we have an opportunity to reach caregivers who otherwise may never have taken advantage of this kind of support
- Continued development in the use of technology in delivery of psychoeducational programs to caregivers caregivers need options to engage in these programs









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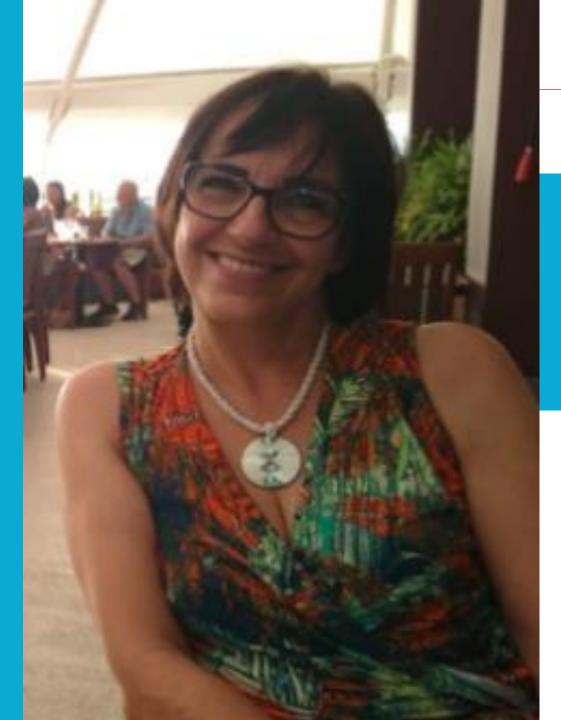


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Global Voices of Caregiving

Mariléia | Brazil





I am Mariléia. I am from Brazil.

Hello, I am Mariléia from the city of São Paulo, Brazil.







Mariléia | Brazil

Did you know that I have taken care of three family members? First, my son who was 11 at the time, now 37.





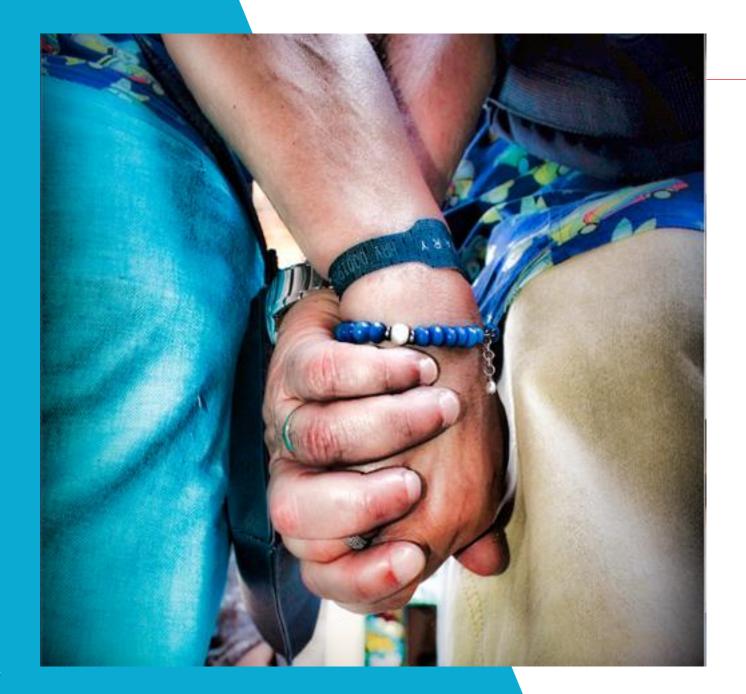


Mariléia | Brazil

At that time, I created a method to face this situation that I called OPAH [which translates to] (prayer, patience, love, and humor). Prayer because this connects us to the Creator. Patience to face the situation. Love [which is] fundamental, in my view, for those who are being cared for. And humor, where the patient needs to know that life is beautiful and we must fight for it. This made all the difference.







Mariléia | Brazil

How to keep OPAH active? In addition to spiritual support, regardless of any religion, professional help like psychotherapy and also the solidarity of close people make all the difference. My vision for a more caregiver-friendly world is to have OPAH in conjunction with professionals.

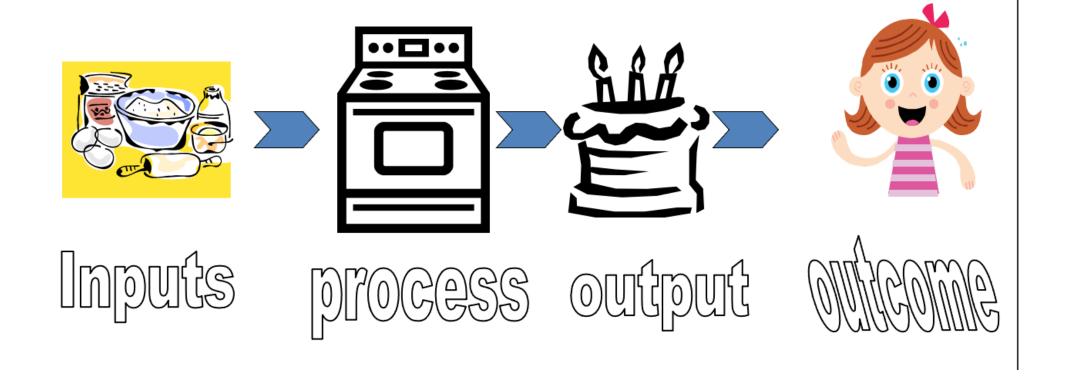


Emma Miller, Social Work and Social Policy

Outcomes for carers

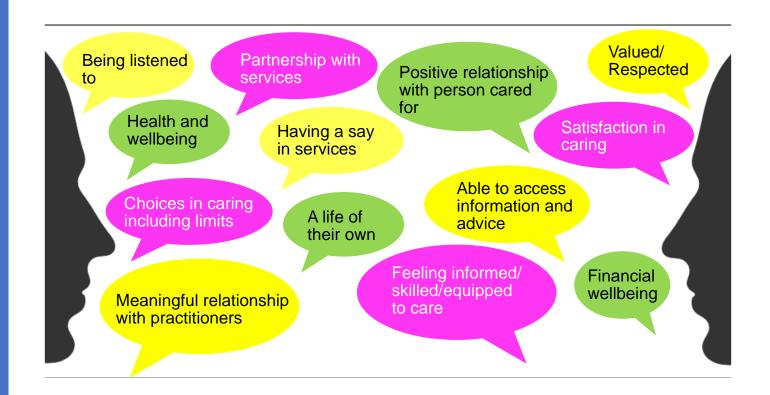
Engage 3.5.22

Change the focus



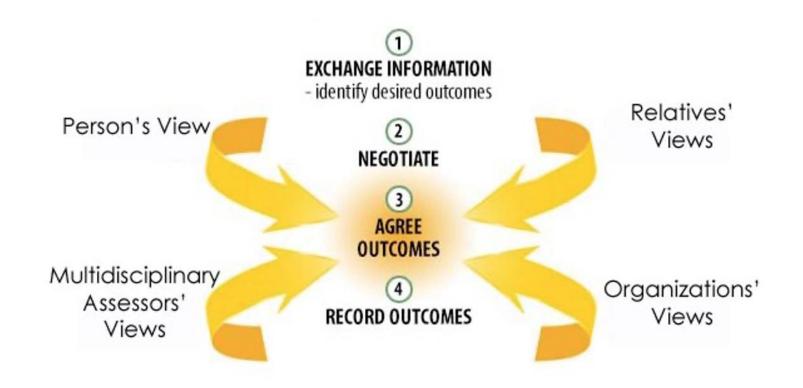
Outcomes for carers

- managing the caring role
- process outcomes
- quality of life of the carer



Exchange model of assessment

Exchange model of Assessment (originally Smale et al)



Reflections on carer outcomes

Avoids assumptions

- Shift from matching deficits to services to engaging with a carer about their life, what matters to them and what needs to change
- Brings carer QoL to the fore
- Opportunity to think in a balanced way about outcomes for the carer and the cared for person
- Evaluation flows with practice rather than cutting against it – every conversation counts
- Strong focus in Carers (Scotland) Act 2016 (also SDS, dementia strategy, GIRFEC etc)

Key elements of the conversation: survey results refined following workshops

- Starts where the person/family is
- Focus on what matters to the person, including what they are hoping for
- Strengths based avoids fixing people and builds on what is already working
- Based on an exchange, blending different perspectives together
- Collaborative and based on partnership
- Listening time to listen, actively and with genuine curiosity
- Consider wider resources, not just formal services, and links to communities
- Action oriented considering what needs to happen



Barriers and gaps

> Practice barriers include

Navigating competing priorities and models

Transition from service led to outcome focus

Fear of raising expectations

Fear of stirring up carer emotions

> Systems barriers include

Service led resource prioritisatoin

Measurement priorities

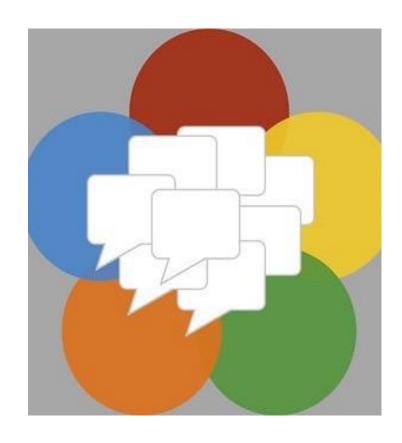
Commissioning

Eligibility criteria



What supports the conversation?

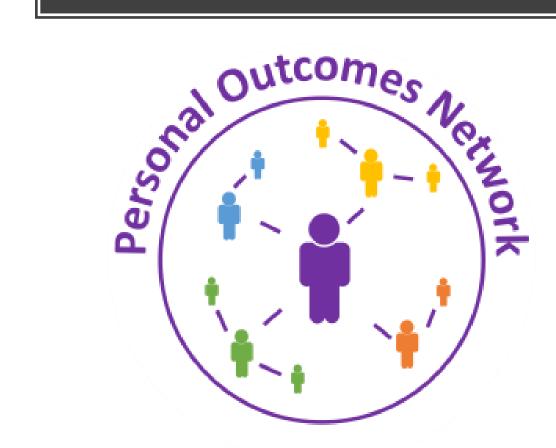
- Time to talk and build relationships
- Practice development and reflective practice
- Peer support feeling connected to allies, honest discussions with managers and peers
- Understanding and belief that it works
- Systems and processes including supervision, paperwork
- Courage and determination
- Whole system approach from values to practice to systems
- Changing the conversation in the organisation as a whole



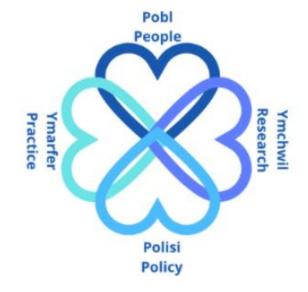
Changing the conversation in the organisation

- Agree I think good conversations approach needs to be shared across the board not just primarily focusing on supported people - but on health and social care staff too to help achieve the cultural shift
- Workers often feel they don't have agency
- Practice makes perfect and sessions like today help
- Role modelling is soooo important, we need to see and feel personal outcomes approaches and conversations in our daily work
- Whole system approach is key workers need to know they are supported in using the approach including support from regulators and other bodies.
- Very interested in how we put the practical steps in place to support staff, not just
 the training and awareness of good conversations and how to have them, but the
 steps to do this within the messiness of real lives and the reflective time to learn and
 grow as professionals. Everyone is so busy and under pressure (front line and
 managers) that it can be difficult to protect that genuinely honest, open learning
 space

Research, policy and practice



Developing evidence Enriched
Practice - DEEP



Short breaks, use of images, carer outcomes





















Carer outcomes – and emotions







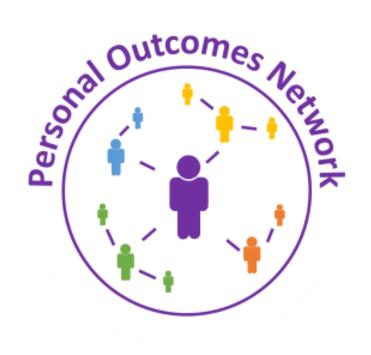












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- e.miller@strath.ac.uk
- @personaloutcom1

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Advancing Economic Security



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Global Voices of Caregiving





I am Akosua.

I am from Ghana.























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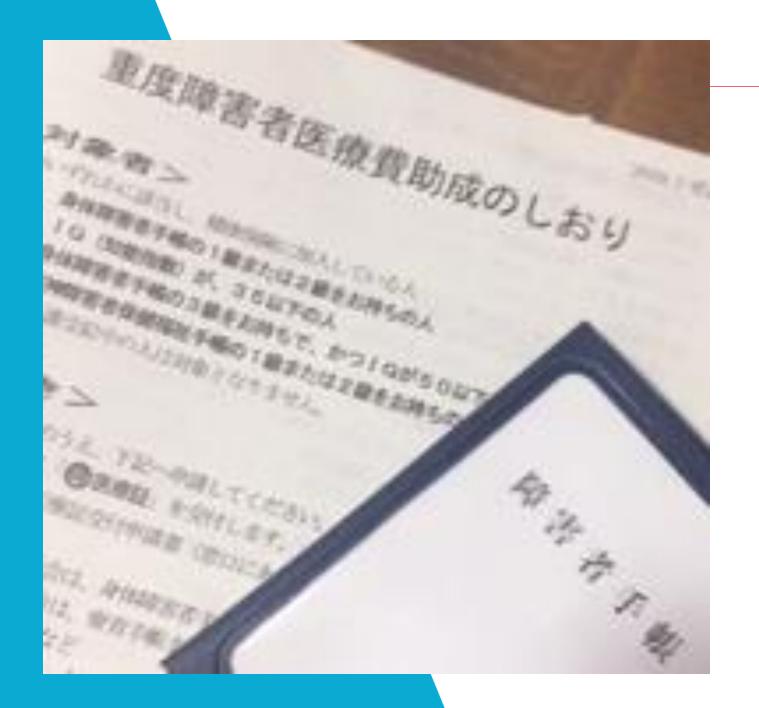
Global Voices of Caregiving





I am Risa. I am from Japan.





















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International – ISO 25551 – General requirements and guidelines for carer-inclusive organizations

Allison Williams, PhD
Convenor to ISO TC314, Working Group 3
Professor, McMaster University
Hamilton, Ontario, CANADA





ISO 25551:2021

Ageing societies — General requirements and guidelines for carer-inclusive organizations

ABSTRACT

PREVIEW

This document specifies requirements and provides guidelines for an organizational program for working carers providing care to:

- adult care recipients (e.g. adults with cognitive, sensory, physical, and invisible disabilities, adults with chronic or episodic conditions and older dependents);
- long-term childcare recipients (e.g. due to chronic illness or permanent cognitive, sensory or physical disability or injury).

This document is applicable to any organization, regardless of size, sector or community setting (i.e. urban, rural or remote).

This document can be used in conjunction with an organization's management systems, human resource programs, and/or equity, diversity and inclusion programs, or on its own in the absence of a formal workplace program to support working carers.



INTERNATIONAL STANDARD ISO 25551

> First edition 2021-11

Ageing societies — General requirements and guidelines for carer-inclusive organizations

Vicillissement de la population — Exigences générales et lignes directrices pour les organisations favorisant et appayant les aidants naturels

News 2022



GUIDANCE FOR ORGANIZATIONS

SUPPORT FOR WORKING CARERS ACROSS THE GLOBE:

ISO 25551:2021 Ageing societies - General requirements and guidelines for carer-inclusive organizations

AS THE WORLD AGES, MORE UNPAID CARE PROVISION IS REQUIRED BY FAMILY, FRIENDS AND NEIGHBOURS

Currently the WHO estimate 349 million people worldwide depend on care, with 101 million of these 60 years of age and older (WHO, 2017). This growing number of unpaid carers are simultaneously employed in the labour market and experience a range of challenges due to the multiple demands of both paid labour and unpaid caregiving. Further, many of these working carers are also caring for young dependents. The vast majority of these unpaid carers are simultaneously working in the labour market or attending school.

Research evidence illustrates that unpaid care work negatively impacts paid work (Korfhage, 2019; Duxbury et al., 2012, Choula et al, 2012, Keating et al, 2013), and few employers have adopted carer-friendly workplace policies. Deficiency of workplace or organizational support could lead to a range of negative employee consequences which increase costs to employers; these include mental and physical health problems, reduced productivity, increased absenteeism and presenteeism, and employees exiting the workforce altogether.

FOR EMPLOYERS TO BEST SUPPORT THESE WORKING CARERS, A SET OF STANDARDIZED GUIDELINES HAVE BEEN CREATED

These were set out by the technical committee on ageing societies in the International Standards Organization (ISO), ISO 25551:2021 Ageing societies — General requirements and guidelines for carer-inclusive organizations Standard published in December 2021.



Developing an International Standard

- Developed under ISO Technical Committee 314 Standards for Ageing Societies
- TC 314 established in 2017 25 participating countries & 16 observers
- Secretariat is British Standards Institute, Chair Britta Berg, AARP
- Have now published 3 standards: age inclusive workplaces, dementia friendly communities and carer- inclusive organizations
- 4 new projects underway: well-being in communities, home health care products and services, age-inclusive digital economy & multigenerational communities
- For more info: https://committee.iso.org/home/tc314

Working Group membership

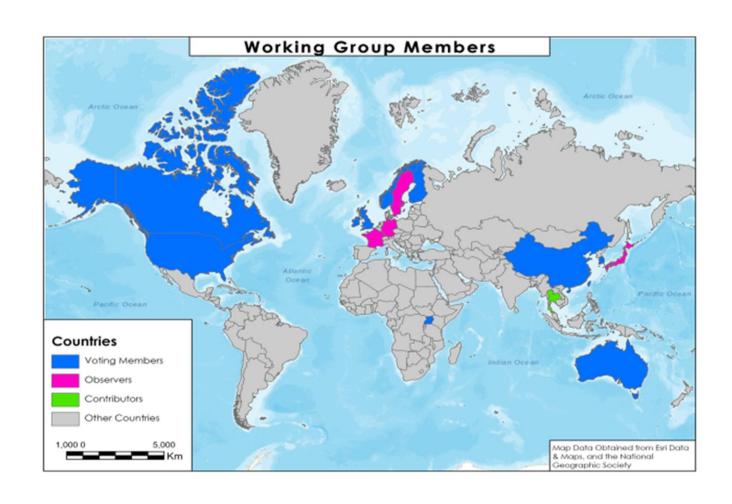


Secretariat: Canada (Standards Council of Canada)

Voting: Canada, USA, UK, Ireland, Australia, Finland, Norway, Uganda, South Korea, China, Singapore, Germany

Observers: France, Japan, Sweden (also comments from Thailand)

Liaisons: ETUC, Eurocarers





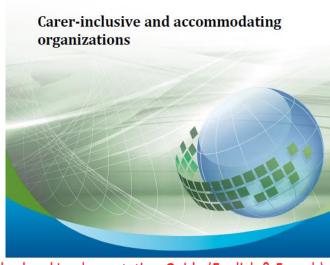
Canadian seed documents CSA Group Standard B-701 & Guide



B701-17



B701HB-18



Helping worker-carers in your organization



Carer-Standard and Implementation Guide (English & French)

https://www.carerscanada.ca/work-care-standard/

https://www.csagroup.org/article/b701-17/?utm_source=carers-canada&utm_medium=web&utm_campaign=b701-17_free_download https://www.csagroup.org/article/b701hb-18/?utm_source=carers-canada&utm_medium=web&utm_campaign=b701hb-18_free_download

Timeline for Development – 3 years



Proposal stage

approval of project & establishment of Working Group (WG)

Preparatory stage

kick off meeting and consultation with WG members on scope and content

Committee stage

• WG meetings to develop content of Committee draft & approval

Enquiry stage

Public review & comment on Draft International Standard (12 weeks)

Approval stage

Approval of Final Draft Standard by full TC 314 Committee

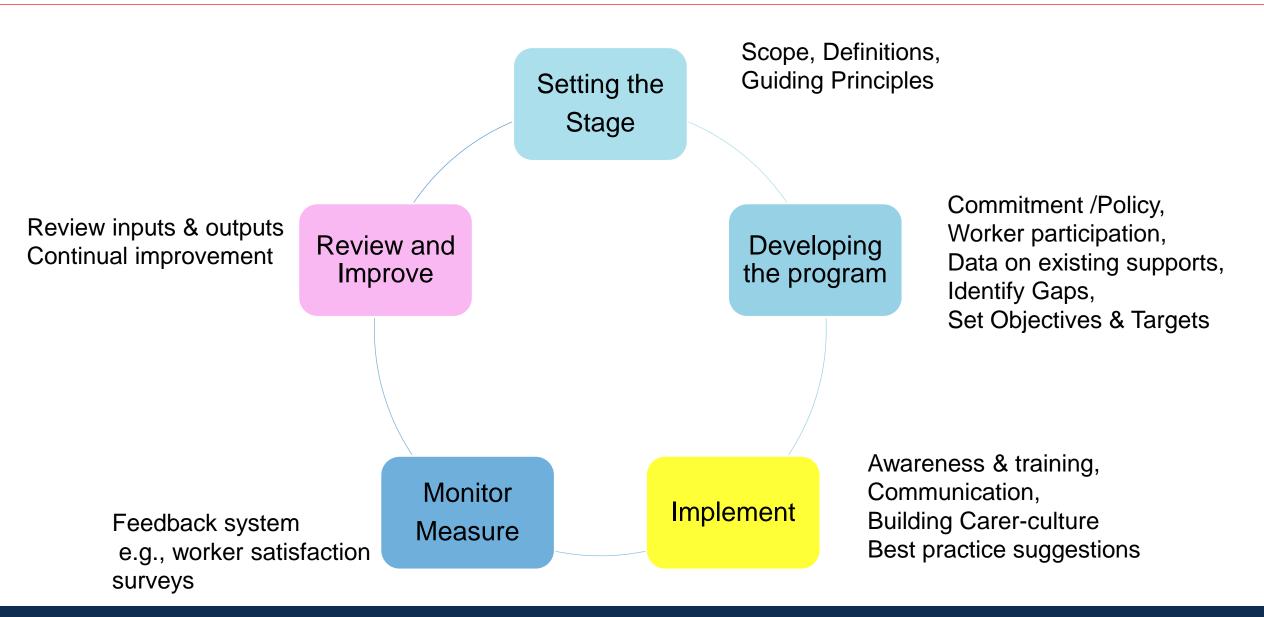
Publication stage

6

Final edit and publication, promotion

Key Elements of Standard







Additional Guidance to help organizations put Standard into practice

Annex A

Sex-/gender-based lens

 Given that organizations are often dominated by one sex or gender (i.e., transport, service sectors) and types of care vary by sex/gender, a sex/gender lens is important to use on data or information related to working carers and carerinclusive organizations in order to gain a more accurate picture to make well informed choices and solutions.

Annex B

Sample internal review checklist

- This sample checklist is provided to help organizations conduct internal reviews as part of the implementation of this document and the ongoing review of the program.
- Smaller and medium-sized organizations can tailor their approach by focusing on key gaps and priorities and implementing the document in a phased manner.



ISO 25551:2021 Ageing societies - General requirements and guidelines for carer-inclusive organizations & UN SDGs

There is no question that gender equality is of critical importance in care work, given that between 57-81% of all unpaid carers are female (depending on the country context) of which most of which are most likely employed outside the home. Further, due to females providing significantly more caregiving hours than males, females experience a greater impact on their paid employment. Females working carers are comparatively more likely to make job modifications, such as changing jobs, as a result of ongoing caregiving requirements. This is reflected in European research that reflects that only half of female working carers are able to work full-time, showing the impact on their financial condition.



Gender Inequality & Reduced Inequalities

The Carer Standard meets a number of UN SDGs, in particular Goal 5: Achieve Gender Equality and Empower All Women and Girls, which is argued as being central to the achievement of all other goals. Goal 5 is made up of 9 targets, including Target 5.4: Value unpaid care and promote shared domestic responsibilities.



Decent Work & Economic Growth

Women make up close to 40% of the labour market internationally. If they are no longer able to be employed due to the demands of their unpaid care work, Economic Growth will suffer. Carefriendly workplace accommodations are central to Decent Work.



Good Health & Well-being

Employment provides not only income for substinence, but the resources, such as vaccinations, health services, and medicine, to acheive Good health & Well-being for carerworkers and their families.



No Poverty

The majority of unpaid carers are female, and due to females providing significantly more caregiving hours than males, females experience a greater impact on their paid employment and are therefore more prone to poverty. Employment is the primary way out of poverty, as well as the primary way to prevent poverty.



Sustainable Cities and Communities

Carer-workers need to juggle both employment and unpaid care work, and do so more successfully when supported in resilient, inclusive Sustainable Cities & Communities.





Challenges in reaching a global consensus

- No existing universal consensus on terms & definitions; terminology is diverse & evolving around the world re: caregiving.
- Need for flexibility around implementation: many countries wanted more guidance to balance key requirements in a voluntary standard, and a phased approach - especially for small organizations
- Traditional gender norms in many countries
- Clarity on how the standard would fit into diverse legal,
 & country-specific programs & supports
- Need to reflect current & emerging issues:
 - Emphasize business case for supporting working carers
 - Impact of pandemic & hybrid work
 - Double-duty carers
 - Disabled carers, & other diversity issues

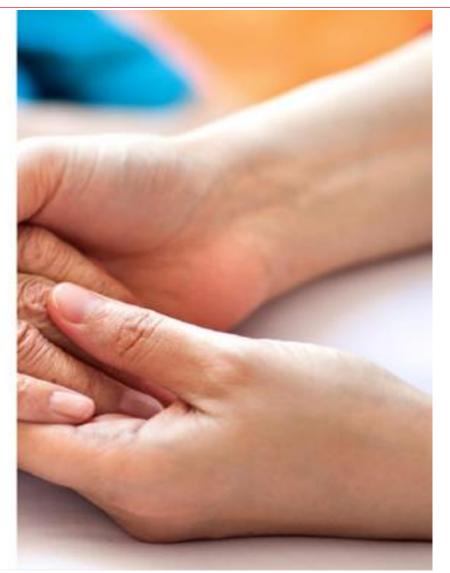


TERMINOLOGY RELATED TO CAREGIVING

An informative guide to commonly used concepts, words and phrases

DEVELOPED BY THE CARER INCLUSIVE WORKING GROUP RESPONSIBLE FOR ISO 25551

please visit our website for more information on ISO 25551 at https://committee.iso.org/home/tc314



Terminology Guide



Glossary

Word/Phrase	Commentary on Use					
care	This a root term and can apply to both paid and unpaid care. Care includes actions which can be social, physical, emotional, spiritual, mental, and financial. Care is provided across a wide variety of settings such as home, community and institutional.					
care partner	Use of this phrase is increasing, particularly in North America and in the chronic disease field. Some stakeholders consider this concept to be more inclusive and egalitarian than carer or caregiver. This phrase is often used in patient and carer engagement activities. However, this term does not clearly distinguish family carers from paid care providers.					
care receiver	These terms are used by organizations or agencies providing care, whether hea social or otherwise. These terms are preferred over the words "patient" or "client".					
care worker	This is a preferred term for paid care providers. Other similar terms include home care provider, care provider, home health care professional, personal support worker, personal care assistant, certified caregiver, professionally trained carer, care specialist, and health care professional.					
caregiver	This phrase is used in many countries to describe any person providing care to a care recipient. It is commonly used in North America to describe family carers. However, this phrase can include both family carers and paid care workers and can cause confusion.					
carer	This phrase is more commonly used in Europe, UK, New Zealand, and Australia. In North America, this phrase is not as commonly used as caregiver or family caregiver. In Asia, this term more commonly refers to a paid care provider.					
	This term is becoming preferred over "caregiver" as care is labour, not a gift. Also, caregiving describes a relationship that is one way – whereas caring recognizes that the act of caring or the role of carer provides value to both the carer and the care recipient.					

helper	This word is used in some countries to refer to those who may not provide regular care but who are involved in helping with a range of caregiving tasks. It is also used to describe those who provide care but who are not affiliated with a formal service provider. In some countries these workers may be from marginalized groups. However, the use of this word is discouraged as it may diminish the value of the support or assistance provided.
informal care informal assistance	This phrase has been widely used but is becoming less acceptable to many carers and experts in the field of ageing, as it does not represent the complexity and the essential nature of the care provided. Unpaid care should be considered as labour and recognized for its value, not only to the care recipients and families concerned, but to the health care system, economy, and society at large. Caring circumstances can vary considerably; the use of this phrase may create and sustain assumptions about family caregiving in that it does not require training, support, and recognition.
informal carer informal caregiver	See commentary for informal care.
leave without pay for the care of immediate family /leave with pay for family-related responsibilities	Some workplaces have started to describe the <i>reason</i> for offering accommodations in workplace policies rather than using a term that describes the role of caregiving.
nonprofessional trained carer	This phrase is often used in Nordic countries to describe relatives or friends who perform unpaid care duties and who have received training to help them provide care that may include medical care. This phrase recognizes the complexity of the care role (e.g. medication management, use of medical equipment, etc.). However, this phrase can be confused with a paid care worker or personal support worker who is not a professional (i.e. nurse, nurse practitioner, doctor, social worker, community paramedic, etc.)
unpaid care	This phrase is preferred over informal care. However, in some countries, health systems and programs are starting to provide payment to family carers; consequently, the distinction between paid and unpaid care is becoming blurred as there is little material difference between a family carer and a professional care

Funding (2017-2025)

SSHRC - CIHR Healthy and Productive Work Partnership Grant

Funding Reference Numbers: HWP – 146001 (CIHR)

890-2016-3018 (SSHRC)









Come visit us!

https://ghw.mcmaster.ca/projects/healthy-productive-workpartnership-grant/

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Annex B – sample checklist



Sample internal review checklist

This sample checklist is provided to help organizations conduct internal reviews as part of the implementation of this document and the ongoing review of the program.

NOTE 1 The levels in column 2 reflect the guidance provided in the document; where a) are requirements and b) are recommendations.

NOTE 2 While this document is applicable to any organization regardless of size or sector, each organization will develop their own program, based on needs and resources of the organization. This checklist can be modified to suit the size, nature and complexity of the organization. It can also be used as a gap assessment tool to highlight those areas requiring further work. Smaller and medium-sized organizations can tailor their approach by focusing on key gaps and priorities and implementing the document in a phased manner.

	Level	Assessment				
Clause		Met	Not Met	Partially Met	Findings	Actions
5.1 You have a document- ed policy and program to support worker carers	a					
5.2 Top management has shown commitment to the implementation of the program	a					
5.3 Workers are engaged in the implementation and maintenance of the pro- gram	ь					
5.4 The organization has a carer-inclusive policy that follows the guiding principles in 4.2	a					
5.5 You have determined whether any local legal requirements apply to the	b					





A VIRTUAL GLOBAL SUMMIT HIGHLIGHTING INNOVATIONS IN CAREGIVING RESEARCH, PRACTICE AND POLICY





Business Champions: Transforming the Workplace for Carers

Helen Walker, Caroline Waters, Nick Baird, Jane Galloway and Jasmine Greenamyer

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Global Voices of Caregiving

Munita | New Zealand





I am Munita. I am from New Zealand.

My name is Munita (Muna) and I live in New Zealand. Me and my 5 kids are caregivers for Abdullah Imtiaz Aziz. Abdullah's dad died when I was pregnant with him. Abdullah was born with congenital heart defects and has had few surgeries. At one of our hospital stays he suffered brain injury due to medical mishap and is now quadriplegic (GMFCS level V).

All of a sudden huge responsibilities fell on us to take care and look after him, and Abdullah siblings automatically became young carers. It's been difficult because we are one adult family but we do it as a family (paternal grandparents help as well) and tackle one day at a time.





Munita | New Zealand

The first photo shows the huge responsibilities that fall on carers, especially the siblings (my kids) and how they feel.

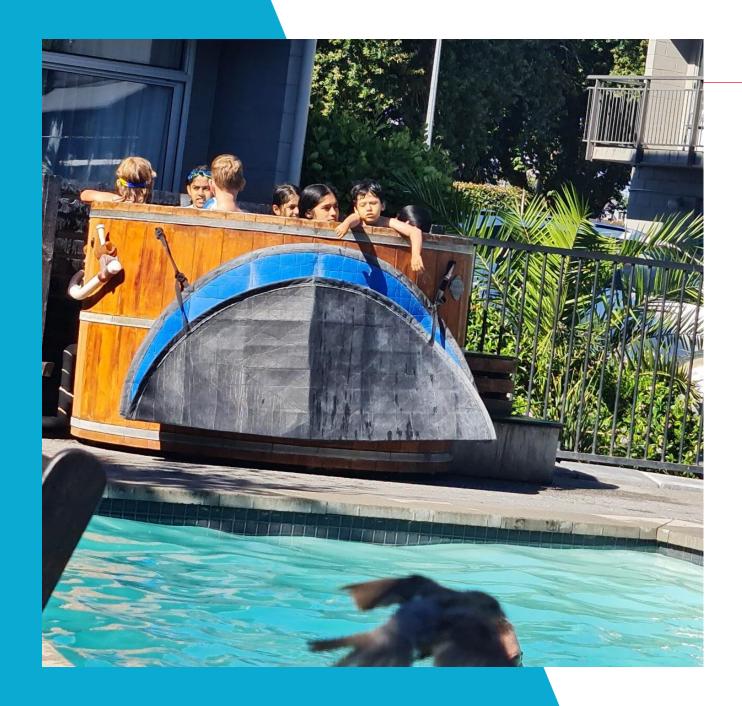




Munita | New Zealand

The second photo shows the solution which would be subsidized or fully paid outings for families to ensure they have fun.





Munita | New Zealand

The third photo shows Abdullah relaxing in tub because if people around you are happy then it flows onto you.



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Global Voices of Caregiving
Zulma | USA



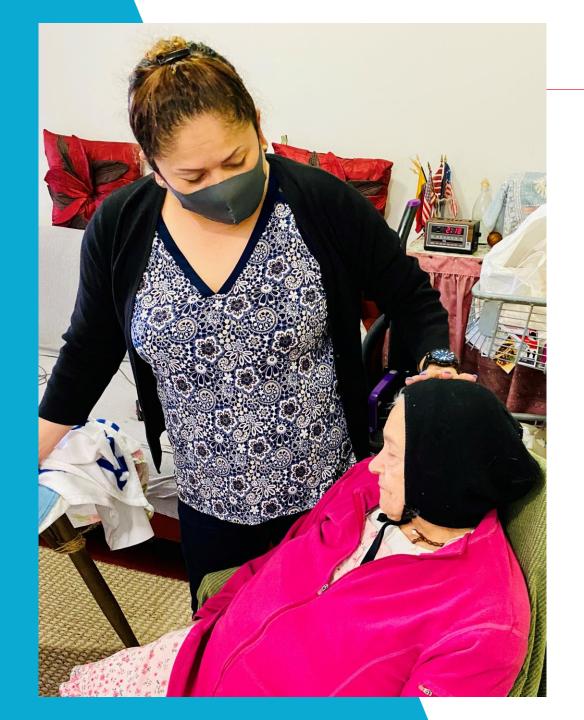


I am Zulma. I am from USA.

Hello! I want to talk a little about my day-to-day work as a caregiver and a little about my personal life. My name is Zulma, I am 48 years old. I came to the United States 28 years ago. Since then, I have focused on improving and giving my best. I have done many different jobs, including cleaning, a little bit of everything in the kitchen, and others. Since 2007, my current job is to be a personal (paid) caregiver.





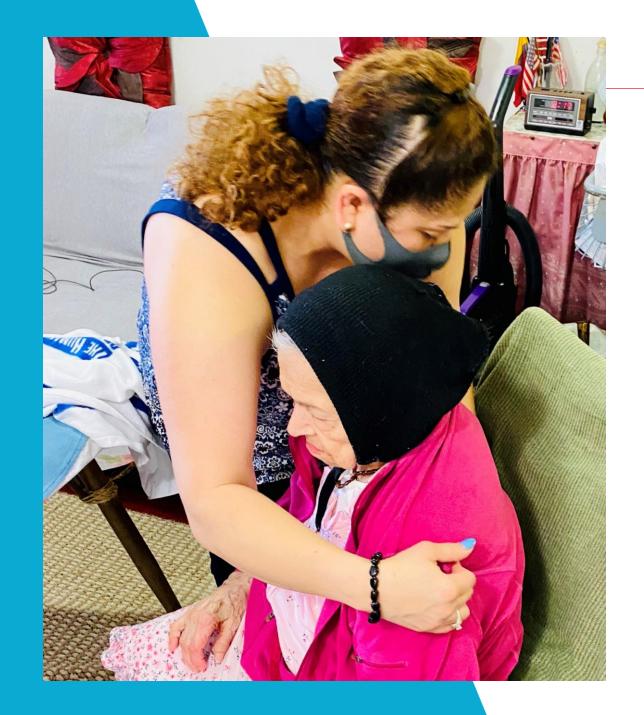


Zulma | USA

As caregivers we have to do different tasks, such as [attending to] their personal hygiene, cleaning the house, washing their clothes, buying food, making them food, and trying to make them independent since that is what it is about. We are personal caregivers for them, but we are here to help make them independent, so that they can still do their things. Also, I want them to feel useful in life. Most older adults feel frustrated because they stop doing the things they did before, and they were never used to someone else doing things for them. When we come to help them, they feel that they are not useful and our struggle is to tell them that for us they mean a lot in our lives—they are even our teachers in life.







Zulma | USA

I could not say that I consider myself as a personal (paid) caregiver. Because for me, I see that we are part of their family, and they are part of ours. We simply need to fill them with affection to make their day more pleasant. During the pandemic, we were essential to them. They could not see their families or friends, so they would only see us (their caregivers). It was difficult; we became psychologists, or rather, a little bit of everything.

It was difficult for me to think that Maria Novoa and Maria Lopez were needing me at that time, and I could not be with them because I had to take care of myself. There were times I asked myself, "my God, and will happen if I can't arrive to take care of them? Will they (other paid caregivers) take care of them just like me?" It is something difficult for us as caregivers.







Zulma | USA

Sometimes I feel frustrated or not taken into account even when living in this country. I am a Salvadoran woman who came to this country at the age of 20 to work, but it has been difficult to get to where I am. Today, I am an American citizen but many times I feel as if I am not, because sometimes I am not taken into account. As caregivers, we do not receive any health benefits, with any company. I cannot plan to have a few weeks of vacation and still get my check; this does not exist in my work. We do not have health insurance that we can cover with the money we earn.

I hope that we will have those benefits (health insurance) that one seeks because then we would all be well and working.





Economic Empowerment for Carers in South Asia

Anil Patil, Carers Worldwide



Family Carers

Who are they?

"Carer" means an individual of any age who cares for or nurses a relative, friend or partner requiring this help due to physical or mental ill health, disability, old age, frailty, substance misuse or any other cause.

In LMIC, they are:

- Invisible
- Isolated
- Vulnerable





79% anxious/depressed



48% physical health problems without treatment



NO respite



Socially excluded and isolated



NO education for young carers



Statistics on Caring

The burden of caring in South Asia

- X 92% of carers in India, Nepal andBangladesh report financial worries
- X Over 75% of carers in Bangladesh report not earning a living
- X 63% of carers in Kathmandu, Nepal report not earn a living
- X 67.5% of carers who are earning a living in Laxmipur, Odisha, India earn less than 1,000 rupees per month



Statistics on Caring

The financial burden of caring in South Asia

Financial Burden

Understanding the issue

Lack of Social Security Provisions for Carers

When carers and cared for individuals do not work, this results in two persons within the same household unable to contribute to the household income

Employers / potential employers do not offer carer-friendly employment policies

Lack of flexible working opportunities often results in carers who do earn a living engaging in precarious, low-paid, informal roles

Primary carers have no-one to share caring responsibilities with

As most carers are women, lack of income-earning opportunities for carers means that women are economically dependent on male household members which perpetuates gender inequality



Who We Are

Our vision and mission

VISION

Our vision is a world in which the needs of every carer are routinely met in order to achieve their physical, emotional, economic and social wellbeing.

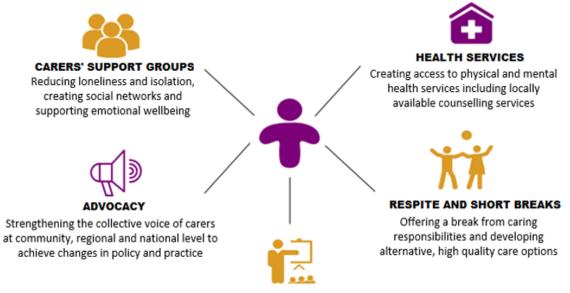
MISSION

Our mission is to enable carers, service providers, policy makers and other stakeholders to recognise and respond to the needs of carers in the developing world, ensuring balance and equal value is given to the needs of the carer and the person receiving care.



What We Do

Our model



EMPLOYMENT, TRAINING AND EDUCATION

Facilitating access to employment, training or education opportunities tailored to exist alongside caring responsibilities



What We Do

Economic Activities









- Carers Groups / Carers Cooperatives for group saving activities that can be accessed for emergencies / livelihood opportunities
- Community Caring Centres providing alternative day care solutions for children with disabilities which gives their carers, usually mothers, free time to earn a living
- Promoting fairer distribution of caring responsibilities among family members so that primary carers have time to earn a living
- Advocating Governments for Social Security provisions for carers
- Supporting carers in accessing existing entitlements for themselves, those they care for, and other household members



What We Do

Economic Activities (cont.)









- Establishing 'revolving funds' through project funding so that carers can access funding to start their own enterprises
- Advocating Government in India to recognise caring as employment under MGNREGA
- Encouraging employers to adopt carer-friendly working policies/practices
- Encouraging microfinance institutions to offer financial products to carers and their families
- Providing skills training and financial literacy training to carers
- Facilitating access to education for child carers so they can enter employment once they become adults



Our Impact

Through Economic Activities

- √ 80% of carers now earning a living, contributing to lifting their families out of poverty
- **✓** 631 Carers Groups and 2 Carers Cooperatives
- ✓ Equivalent of £69,670 saved in Group Savings Accounts
- **✓ 24 Community Caring Centres**
- √ 6,735 carers accessing employment/training support through Government
- √ 312 young carers back in education
- ✓ Equivalent of £859,513 of Government Support accessed

- Chinthadevi, from Ham Nari village in Jharkhand cares for her husband, Mahendra, who is severely mentally ill and also has epilepsy
- She used to borrow money often to purchase her husband's medicine and also just to make ends meet
- Took a loan from her local carers group to set up a small shop from which she sells supplies and snacks like pakora and bhajis
- ➤ Is now earning Rs 600-800 per day, a healthy income which makes her family financially stable



Success Story

Group Livelihood Activity

- Maa Sarala Carers Group in Odisha participated in a three-day livelihood workshop in June 2019
- Soon after, the Group started a Jackfruit Chips production enterprise
- ➤ The group accessed a start-up loan to purchase utensils and raw materials
- The group produces and sells an average of 10-15kg of chips per day



Success Story

Individual Livelihood Activity



Success Story

Advocacy and Social Security

- Appointed as Nodal Agency by State Government of Karnataka and recognised as Domain Expert by Karnataka State Legal Services Authority
- Advocated on behalf of carers for the adoption of a Carers Allowance under Rights of Persons with Disabilities Act, 2016. Have achieved significant gains in Karnataka with some Districts providing Carers Allowance based on our recommendations.
- Inclusion of 'carers' question in upcoming census in Karnataka will identify scale of caring and could result in more carers accessing Carers Allowance in the District





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embracing carers

Thank you!

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