Welcome!

May 19, 2022 8:00 am – 6:00 pm ET
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.
Shiang | Taiwan
Shiang | Taiwan
In Loving Memory

Shiang | Taiwan

In Loving Memory
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.
Promoting Mental and Emotional Health and Wellbeing
Global Voices of Caregiving

Mami | Japan
I am Mami.
I am from Japan.
Mami | Japan
Mami | Japan
Mami  |  Japan
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.
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.
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 of 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.
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.

Anat | Israel
Global Voices of Caregiving

Vinicius | 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.
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.
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.
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

#WCC22 #worldcarers
“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

NOW – over 250,000 items on ‘young carers’ in Google Scholar
Becker & Leu Classification 2016, 2021

Classification 2016

Updated classification 2021


Psychosocial Support for Promoting Mental Health and Well-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% cf 13% UK]

Family’s health conditions
Physical disabilities 46%
Mental illness 40%
Cognitive impairments 26%
Addiction 10%
Friends: 69% have mental illness [82% UK cf 30% Italy]
**General findings**

- Amount of caring (MACA) varies between countries.
- Female AYC do significantly more caring in Netherlands and UK.
- Both positive and negative adaptation is found.
- AYC 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)

![Graph showing the relationship between country-level responses and outcomes]
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
1. 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

First news post

This is the first of many news posts to come. It is an exciting time as this app is currently under development and without the help from the pilot users we shall be quite lost indeed. It is essential that we get feedback on what you think is good or bad about the app. How can it be improved? Is there anything you are missing? Does the app feel and look right? These are just some of the relevant questions. We at the Me-We project could not be more thankful for your participation and are looking forward to hearing your thoughts.

The app itself is intended to be in its complete form by June this year. So until then there is much to do, but with feedback and great input we shall surely create an app that can be of use to young carers in their day-to-day lives.

0 Comments
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?
Contact details

Elizabeth Hanson
• Email: elizabeth.hanson@lnu.se
• Phone: +46703614846

Saul Becker
• Email: saul.becker@sussex.ac.uk; sbeckermail@gmail.com
• @profsaulbecker

Feylyn Lewis
• Email: feylyn.m.lewis@vanderbilt.edu
• Phone: +1 615-322 7980
• @DrFeylynLewis
• www.drfeylynlewis.com
Global Voices of Caregiving

Jean | Taiwan
Hello, my name is Jean. I am from Taiwan.
Jean | Taiwan
Jean | Taiwan
Jean | 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

World Carers Conversation, May 18, 2022
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
Integrating Caregivers to the Healthcare Team
Global Voices of Caregiving

Nelly | Taiwan
I am Nelly.
I am from Taiwan.
Nelly  |  Taiwan
Nelly | Taiwan
Global Voices of Caregiving

Mr. Terashima | Japan
I am Mr. Terashima.
I am from 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.
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.
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 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.
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
• 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

**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

Tested in 11 sites across the U.S.
1) **basic care** (transferring, dressing, toileting) module, facilitated by the PT and OT professionals,

2) **Communication and feeding module**, facilitated by the SLP professionals,

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

4) **young caregivers and ALS support**, facilitated by the social work and care services professionals

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

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

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 assumptions 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......

- Need to conduct it in community – not in health care settings. Transportation is an issue
- Be flexible with professionals who deliver training
- Create handbook – pictures and wording that reflects cultures
- Engage parents – make training more family based
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?

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

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

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

- 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.
Next steps

- 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
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/

Melinda S. Kavanaugh
kavanaugh@uwm.edu

Franclo Henning
fhenning@sun.ac.za
Global Voices of Caregiving

Marcelo | 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.

I am Marcelo.
I am from 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!
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!
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!
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
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

Researchers
- Julian Montoro-Rodriguez, PhD, Professor of Sociology, University of North Carolina, Charlotte
- Dolores Gallagher-Thompson, PhD, Professor Emerita, Stanford University School of Medicine
- Ann Choryan Bilbrey, PhD, CEO, Optimal Aging Center, Sunnyvale, CA
- Jennifer Ramsey, PhD, Case Western Reserve University, Cleveland, OH
- Larry Wolford Thompson, PhD Founder & Co-Director, Optimal Aging Center
- Bruno Kajiyama, MS Founder and CEO, Photozig, Inc.
- Kendra Jason, PhD, Associate Professor, Dept. of Sociology, UNC Charlotte

Facilitators
- Angela Burrow, CDP CADDCT
- Fallon J. Richie, M.A., UNC Charlotte
- Amy Royal, M.A., UNC Charlotte
- Sheryl Gerrard, M.A., Jewish Family Services of Greater Charlotte, Inc.
- Leah Cooper, MHDL, CCMT
- Katie Cooper, MSW, Memory and Movement, Charlotte

Advisory Board
- Tracy McGinnis, Southminster
- Janet LeClair, Memory and Movement Charlotte
- Deryl Fulmer, PhD, NCRGEA
- Connie Bonebrake, MSW, Humana
- Pam Hurley, Faith Community Health Ministry, Atrium Health
- Renee Rizzuti, PACE of the Southern Piedmont
- Britney Kearney, PACE of the Southern Piedmont
- Ann Marie Worman, Parkinson Association
- Mike Mannion, Senior Care Authority
- Hiep Pham, MD, Charlotte NC

This work was supported by Southminster Community Fund.
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
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

TeleSavvy² (USA)
Online Stress Management Training Program³ (Canada)

iSupport⁴ (Brazil)

understAID⁵ (Denmark, Poland, & Spain)
iSupport⁶,⁷ (Portugal, Switzerland)
iSupport⁸ & ¹⁰ (India & Vietnam)
Online Elderly Care⁹ (Thailand)
iSupport¹⁰ (Australia & New Zealand)
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\textsuperscript{11, 12}
- Better quality of care & increased safety\textsuperscript{13, 14, 15}
- Improved quality of life for care recipients\textsuperscript{12, 13}
- Can delay patient institutionalization\textsuperscript{12, 16}
- Cost savings through lower rates of healthcare utilization & reduced readmission rates\textsuperscript{17}

But these benefits come at a high cost to the caregivers themselves\textsuperscript{18}
- 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 care-recipient
  • 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
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
The Intervention

Ann Choryan Bilbrey, PhD
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 with 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?
Caregiver TLC was sourced from Coping with Caregiving
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)
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.
Methodology

Jennifer Ramsey, PhD
Methodology: Conceptual Model

**Context**
Demographics
- Age
- Sex
- Race
- Education

**Stressors**
- ADL/ IADL
- Perceived Burden
- Perceived Health

**Resources**

**External resources**
- Income
- Social Support

**Internal resources**
- Emotional Coping
- Self-Efficacy
- Caregiver Gains

**Proactive behavioral adaptations**

*Caregiver TLC Program Skills*
- Recognition of Stress Signs, Deep Breathing, Visualization
- Behavioral Activation (Positive Activities)
- Balanced Worldview (finding the positive), Altas CareMap (care network)
- Finding small self care things to do, Sleep Hygiene, Cognitive Barriers
- Using Physical Signs and Thoughts to Identify Emotion, S.T.O.P Technique
- Various ways to stay connected via online means

**QOL outcomes**
- Anxiety
- Depression
- Nursing Home Placement

Conceptual Model showing potential predictors for caregiver outcomes adapted from Kahana, Kahana & Lee (2014).
Methodology: Participant Flow and Experimental Design

CG Registration and Screening:
• [https://fcrc.charlotte.edu/](https://fcrc.charlotte.edu/) (Qualtrics survey)

Do Not Meet Criteria:
Q20 Thank you for participating in this survey. As you provide less than 4 hours of care per week, you do not qualify for the current program. You may qualify for future programs. Can we keep your information on file and reach out to you with information on programs in the future?
  ○ Yes, I consent to be placed on a waiting list. (1)
  ○ No, I do not consent to be placed on a waiting list. (2)

Continuing Conversations
• Emailed invitations to Continuing Conversation webinars

Meet Criteria:
• Added to waitlist/assigned to group
• Emailed consent form and link to electronic consent form (Qualtrics)
• Contacted via phone to complete tech survey (Qualtrics)
• Confirm availability via email or phone

Experimental
• technology training as needed via phone and Zoom

Time 1 assessment
• completed via phone (Qualtrics)

Caregiver TLC Workshop
• Emailed link and password to Participant Page: [https://caregivertlc.org/participants.html](https://caregivertlc.org/participants.html)
• Emailed Zoom invitation to Workshop sessions

Time 2 assessment
• completed via phone (Qualtrics)

Control
• technology training as needed via phone and Zoom

Time 0 assessment
• completed via phone (Qualtrics)

Wait six weeks

Wait two months

Time 3 assessment
• completed via phone (Qualtrics)
• 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

- Total Screened: (n = 135)
  - Eligible (n = 128)
  - Excluded (n = 7)

  - Waitlist (n = 48)
  - Randomized/Consented (n = 60)
    - Withdrew Before Randomization (n = 20)
      - Exp.: Groups 1, 3, 5, 7 Assigned (n = 28)
        - Active (n = 21)
        - Baseline [T1] (n = 28)
        - Post-test [T2] (n = 17)
        - 2 Month [T3] (n = 2)
      - Control: Groups 2, 4, 6, 8 Assigned (n = 30)
        - Active (n = 23)
        - Control [T0] (n = 31)
        - Baseline [T1] (n = 25)
        - Post-Test [T2] (n = 17)
        - 2 Month [T3] (n = 5)
Engagement

Angela Burrow, CDP CADDCT
“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

Welcome to companion webpage for participants of the Caregiver TLC program.

Workshop Content

Materials

Continuing Conversation Videos

Welcome

Welcome to companion webpage for participants of the Caregiver TLC program.

Workshop Content

Materials

Make-up Videos

Welcome Page

Welcome to companion webpage for participants of the Caregiver TLC program.

Online Resources

Resources

Strategies for Stress - Resources (Optional)

Continuing Conversation Videos

Thank you for your interest, and participation in the Caregiver TLC Program, an effort to continue providing beneficial information and support to caregivers, family, and the elderly family member you are caring for. New themes for 'Continuing Conversations,' please see below for recordings of these themes to assist you in addressing the care one receives.
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)
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
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

[^20]: Source: Institute for Local Self-Reliance/AARP *Exploring Digital Equity Fact Sheet Series*
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-term\textsuperscript{17}

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
References
References


References


Global Voices of Caregiving
Mariléia | Brazil
Hello, I am Mariléia from the city of São Paulo, Brazil.
Did you know that I have taken care of three family members? First, my son who was 11 at the time, now 37.
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.
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.

Mariléia  |  Brazil
Outcomes for carers
Engage 3.5.22
Change the focus

Inputs → process → output → outcome
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 prioritisation
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 sooo 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

Personal Outcomes Network

Pobl People
Ymarfer Practice
Polisi Policy
Ymychwil Research
Short breaks, use of images, carer outcomes
Carer outcomes – and emotions
Contact details and references

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

Miller, E., Seddon, D., Toms, G. and Hanson, E. (Under review) Talking About What Matters: a scoping review exploring outcome focused conversations with adult carers


Miller, E. and Barrie, K. (2019) Narrative recording as relational practice in social services: a case study from a Scottish carer support organisation, *British Journal of Social Work* [https://doi.org/10.1093/bjsw/bcz100](https://doi.org/10.1093/bjsw/bcz100)
Advancing Economic Security
Global Voices of Caregiving

Akosua | Ghana
I am Akosua.
I am from Ghana.
Akosua | Ghana
I am Risa.
I am from Japan.
重度障害者医療費助成のしおり

対象者

身体障害者手帳の1級または2級をお持ちの人

手帳の1級または2級をお持ちの1級または2級をお持ちの人

手帳の1級または2級をお持ちの1級または2級をお持ちの人
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

#WCC22  #worldcarers
ISO 25551:2021
Ageing societies — General requirements and guidelines for carer-inclusive organizations

ABSTRACT
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.
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](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

Carer-Inclusive and Accommodating Organizations

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

Timeline for Development – 3 years

1. **Proposal stage**
   - Approval of project & establishment of Working Group (WG)

2. **Preparatory stage**
   - Kick off meeting and consultation with WG members on scope and content

3. **Committee stage**
   - WG meetings to develop content of Committee draft & approval

4. **Enquiry stage**
   - Public review & comment on Draft International Standard (12 weeks)

5. **Approval stage**
   - Approval of Final Draft Standard by full TC 314 Committee

6. **Publication stage**
   - Final edit and publication, promotion
Key Elements of Standard

Setting the Stage

Scope, Definitions, Guiding Principles

Commitment /Policy, Worker participation, Data on existing supports, Identify Gaps, Set Objectives & Targets

Review and Improve

Review inputs & outputs
Continual improvement

Developing the program

Awareness & training, Communication, Building Carer-culture, Best practice suggestions

Monitor Measure

Feedback system
e.g., worker satisfaction surveys

Implement


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 carer-inclusive 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 Care 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. Carer-friendly workplace accommodations are central to Decent Work.

Good Health & Well-being
Employment provides not only income for sustenance, but the resources, such as vaccinations, health services, and medicine, to achieve Good health & Well-being for carer-workers 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
## 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 recipient** | These terms are used by organizations or agencies providing care, whether health, social or otherwise. These terms are preferred over the words “patient” or “client”.

**care receiver** | 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.

**care worker** | 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.

**caregiver** | This phrase is more commonly used in Europe, UK, New Zealand, and Australia. In North America, this phrase is not as commonly used as carer 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** | 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. 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 assistance** | See commentary for informal care.

**informal carer** | Some workplaces have started to describe the reason for offering accommodations in workplace policies rather than using a term that describes the role of caregiving.

**informal caregiver** | 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.)

**leave without pay for the care of immediate family /leave with pay for family-related responsibilities** | 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 provider.
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-work-partnership-grant/

Allison Williams awill@mcmaster.ca
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.

<table>
<thead>
<tr>
<th>Clause</th>
<th>Level</th>
<th>Assessment</th>
<th>Findings</th>
<th>Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1 You have a document- ed policy and program to support worker carers</td>
<td>a</td>
<td>Met</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.2 Top management has shown commitment to the implementation of the program</td>
<td>a</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.3 Workers are engaged in the implementation and maintenance of the program</td>
<td>b</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.4 The organization has a career-inclusive policy that follows the guiding principles in 4.2</td>
<td>a</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.5 You have determined whether any local legal requirements apply to the</td>
<td>b</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Business Champions: Transforming the Workplace for Carers

Helen Walker, Caroline Waters, Nick Baird, Jane Galloway and Jasmine Greenamyer
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.
The first photo shows the huge responsibilities that fall on carers, especially the siblings (my kids) and how they feel.
The second photo shows the solution which would be subsidized or fully paid outings for families to ensure they have fun.
The third photo shows Abdullah relaxing in tub because if people around you are happy then it flows onto you.
Global Voices of Caregiving

Zulma | 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.
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.
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.
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
“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
Statistics on Caring

The burden of caring in South Asia

- 84% female
- 79% anxious/depressed
- 48% physical health problems without treatment
- NO respite
- Socially excluded and isolated
- NO education for young carers
92% of carers in India, Nepal and Bangladesh report financial worries

Over 75% of carers in Bangladesh report not earning a living

63% of carers in Kathmandu, Nepal report not earn a living

67.5% of carers who are earning a living in Laxmipur, Odisha, India earn less than 1,000 rupees per month
Financial Burden
Understanding the issue

Lack of Social Security Provisions for Carers

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

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
Who We Are

Our vision and mission

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.

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.
What We Do

Our model

- **CARERS’ SUPPORT GROUPS**
  Reducing loneliness and isolation, creating social networks and supporting emotional wellbeing

- **HEALTH SERVICES**
  Creating access to physical and mental health services including locally available counselling services

- **ADVOCACY**
  Strengthening the collective voice of carers at community, regional and national level to achieve changes in policy and practice

- **RESPITE AND SHORT BREAKS**
  Offering a break from caring responsibilities and developing alternative, high quality care options

- **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
➢ 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
➢ 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
Thank you!

#WCC22  #worldcarers