Advancements in Caregiver Support in the United States

Richard C. Wender, MD
Chief Cancer Control Officer
American Cancer Society

Disclosure of interest: None declared
Global Burden of Cancer Among Women

- Cancer is a leading cause of death among women in both high- and middle-income countries, but the burden is expanding at all income levels due to population growth and aging.
- As women are living longer, cancer is emerging as major health challenge in LMICs.
Factors

• Cancers that were common only in high-income countries are becoming more prevalent due to:
  – longer life expectancies
  – changes in reproductive patterns
  – influences from the west, such as smoking, obesity, and physical inactivity
The Economic Burden of Cancer

• $286 billion estimated global economic burden in 2009, including:
  – Medical costs
  – Non-medical costs, such as transportation and caregiving
  – And productivity losses

• In the US alone in 2006, years of productive life lost equaled $82 million USD.
Caregiver support is crucial to the physical and emotional well-being of people with cancer.
The Role of Caregivers

- information on how to provide care (cancer, its treatment, long-term and late side effects)
- emotional support/stress management (anxiety/depression/fear/anger)
- shared responsibilities for medical decisions
- communication and problem-solving skills
- financial concerns/employment benefits
- respite services/social support
- instrumental support (cooking, transportation)
- managing their own wellness, health, and health behaviors
Caregiver Profile

• Emotional distress (especially guilt)
  – Physical demands
  – Activity restrictions
  – Altered job responsibilities and financial hardships

• Poorer caregiver quality of life associated with
  – Female
  – Younger age
  – Caring for a parent
  – Caring for the survivor AND small children

• Positive effects
  – Post-traumatic growth/benefit-finding
  – Improved self-esteem and self-worth
  – Satisfaction with life
Caregiver
Unmet Needs
Across
Trajectory

2 months post-diagnosis
2 years post-diagnosis
5 years post-diagnosis

Psychosocial
Medical
Daily Activity
Financial

Caregivers’ Top 5 Unmet Needs

- Helping the survivor with his/her emotional distress (i.e., anger, anxiety, depression, fear, etc.)
  - 47.5% in 2 mo
  - 38.4% in 2 yr
  - 30.8% in 5 yr

- Dealing with your emotional distress (e.g., anger, anxiety, depression, fear, resentment, etc.)
  - 29.6% in 2 mo
  - 30.8% in 2 yr
  - 26.5% in 5 yr

- Dealing with lifestyle changes
  - 29.6% in 2 mo
  - 26.5% in 2 yr
  - 26.5% in 5 yr

- Getting information about the cancer he/she was diagnosed with (e.g., prognosis, treatment, etc.)
  - 46.3% in 2 mo
  - 26.5% in 2 yr
  - 26.5% in 5 yr

- Talking to the survivor about his/her concerns
  - 31.5% in 2 mo
  - 25.6% in 2 yr
  - 7.1% in 5 yr
Caregiver-Specific Resources and Support
ACS Caregiver Resource Guide
Caring for a Loved One with Cancer

Caring for a Loved One with Cancer

What is a Cancer Caregiver? ........................................... 1
What Does a Caregiver Do? ....................................... 1
What Does It Feel Like to Be a Caregiver? ................... 3
What If You Don’t Want to Be a Caregiver? ............... 4
You’ll Need to Take Care of Yourself Too...................... 6
Take a Break or Time for Yourself ............................. 7
Over Your Limitations, ............................................. 8
Finding Support for Yourself..................................... 9
Ask Others to Help .................................................. 9
Caring for Your Children During This Time ............. 12
Raising a Caregiver and Keeping Your Job ............. 13
Keeping Your Health Insurance If You Have
to Quit Your Job .................................................. 14
If You Make Mistakes ............................................. 15
Making Health Insurance Decisions as a Cancer Caregiver .. 16
ACS Caregiver Resource Guide

Online interactive guide available at cancer.org/caregiverguide

- Cancer Caregiving
- Caregiver Self-Care
- Communication
- Cancer Information
- Cancer Treatment
- Patient Nutrition
- Coping
- Caregiver Resources

@RichWender
Caregiver Support Suite Videos

Caregivers are a crucial part of any cancer care team. The goal of this educational video series is to support caregivers with the everyday needs of cancer patients and to provide self-care techniques to improve their quality of life during this difficult time.

**Caregiver Series Categories**

**Managing Side Effects**
One 60-90 second video covering the most common cancer treatment side effects: nausea, diarrhea, fatigue, “chemo brain” & sleep disturbances. We will feature a field expert explaining each side effect and offering tips on managing them.

**Physical Care Training**
Five 30-60 second videos delivered by a field expert with a “patient” example offering specific steps & tips for the following subjects: port care, drain care, signs of infection, medication management & pain management.

**Communication**
One 60-90 second video offering caregivers tips on how to ask for help, asking the right questions, speaking with help professionals, and advocating for patients’ health.

**Self-Care**
Four 30-90 second videos from a field expert on the following subjects: Coping & stress management, fear of recurrence, exercise & nutrition, and deep breathing/meditation techniques.
The American Cancer Society is a nationwide, community-based voluntary health organization dedicated to eliminating cancer as a major health problem.

1. 800. 227. 2345 / cancer.org

Embracing Carers™ is an initiative led by EMD Serono, in collaboration with leading caregiver organizations around the world, to increase awareness and action about the often-overlooked needs of caregivers.

embracingcarers.com
• Managing treatment side effects
• Navigating FMLA
• Managing financial and insurance issues
• Tips on coordinating care
• End-of-life care
• Caring for a child with cancer
• Online support communities
Cancer.org/bookstore
Embracing Carers china results & Merck Initiatives

Merck’s commitment to improving women’s health and prosperity for economies

BoonHuey Ee,
Country President, Merck Biopharma Taiwan

October 2nd, 2018
Agenda of my talk

1 Unveil China Embracing Carers survey findings

2 Highlight Merck’s global Healthy Women Healthy Economies initiative to elevate the often-overlooked and unique needs of women.
China healthcare Landscape

Vast country, growing population, & huge health disparities

1.3B+ Population
The nation’s population will peak at roughly 1.45 billion by 2030 and then hover around 1.4 billion until the middle of the century

48.5% Women
The gender imbalance is slightly wider than the global average, with women making up 48.5 percent of the population

4-2-1 Result of 1 child policy
Caring for 4-6 older people
One child, two parents and four grandparents concept- as a result of one child policy, a single child may be responsible for the care of four or six older people

150M Elderly population
Over the past 20 years the number of people aged 65+ has nearly doubled reaching 150 million (10.8% of the total population) according to the Ministry of Civil Affairs

US$750B Elderly healthcare spend
It is estimated that total spending on the elderly care will reach RMB 5 trillion by 2050

Y2030 Healthy China: vision to action
Development of a ‘Healthy China’ is central to the Chinese Government’s agenda– health is a prerequisite for people’s all-round development and a precondition for economic and social development
Embracing Carers wishes to gain an understanding of current carer challenges to aid discussion on how we can better improve the lives of carers across China

**Topline Results:**

1. **Family Life**
   - 98% of informal carers feel supported by their family
   - 68% of informal carers care for their parent / parent-in-law
   - Over half (55%) of informal carers don’t spend as much time with their children as they would like
   - Positive family support
   - Lacking time with children

2. **Support from Authorities**
   - 83% of informal carers feel supported by the government
   - 88% of informal carers feel supported by their local health authority / services
   - Over half (54%) of informal carers feel their role is unrecognised by their healthcare system
   - Government support
   - Local health authority support
   - Carers feel unrecognised

3. **Effects on Lifestyle**
   - Nearly half (48%) informal carers have had to reduce the hours they work to care for a family member
   - Over a third (35%) of informal carers living in suburban areas feel being a carer has put pressure on their finances
   - Reducing working hours
   - Financial pressures

Development of a 17 question survey of carers across China to determine views and attitudes towards their caring role including impact of lifestyle, finances, emotional and physical health; Conducted with Censuswide and Chinese partner Viga; The research was conducted by Censuswide, 502 Informal/unprofessional carers aged 18-75 years (a minimum of 300 respondents aged 35-55) in China between 02.07.2018 - 10.07.2018
Embracing Carers wishes to gain an understanding of current carer challenges to aid discussion on how we can better improve the lives of carers across China

*Topline Results continued:*

4. Health and Wellbeing of Carers
   - Nearly two thirds (65%) of informal carers don’t have time to book or attend medical appointments for themselves
   - Over three quarters (77%) of informal carers feel tired most of the time
   - 43% of informal carers have feelings of depression
   - Nearly two thirds (65%) of informal carers don’t have time to book or attend medical appointments for themselves
   - Over three quarters (77%) of informal carers feel tired most of the time
   - 43% of informal carers have feelings of depression

5. Where Carers Live
   - Three quarters (75%) of informal carers living in rural areas said that it worries them to ask for help to address their own health
   - 58% of informal carers living in rural areas feel a lot of pressure to be a so-called ‘informal carer’ (compared to 23% in urban areas)
   - Urban dwelling carers seem to not feel under so much social pressure in their caring role and 25% don’t see it as a second job
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6. Communication
   - 67% of informal carers would find it essential to exchange their experiences with other carers through WeChat groups
   - 78% of informal carers in suburban areas would find it essential to exchange their experience with other informal carers through WeChat groups, compared to 44% living in rural areas and 68% in urban areas
   - 67% of informal carers would find it essential to exchange their experiences with other carers through WeChat groups
   - 78% of informal carers in suburban areas would find it essential to exchange their experience with other informal carers through WeChat groups, compared to 44% living in rural areas and 68% in urban areas

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In China, provincial economic development is distinct and diverse, & the implementation of national policies varies on provincial & even city level.
Merck’s commitment to an initiative that links women’s health and prosperity for economies
We see the bigger picture of how health and prosperity are intertwined for women, and we are committed to doing our part.

The importance of family is firmly rooted within our 350-year-old history, and our ongoing commitment to focusing on caring for patients and their families is part of our DNA. As a provider of solutions for diseases that affect women disproportionately, we are investing in initiatives to improve major aspects of women’s health from awareness to education, access to healthcare, and government programs.

We have a responsibility to do better.
Healthy Women, Healthy Economies

Established APEC 2014

- Merck is the founding private sector partner collaborating with 21 APEC Economies, led by the United States and the Philippines
- In August 2015, an Experts Group came together in Manila to form a Policy Toolkit informed by a literature review
- Implementation workshops held annually since 2015
Healthy women, Healthy Economies

Sustainable economic growth cannot be achieved if women, who consist of half the workforce, are unable to fully participate in the economy due to health implications.

The number of women across the globe who are not reaching their economic potential due to preventable causes.

Estimated amount that would be added to the annual global GDP by 2025 if women were to participate in the economy at the same level as men.

865 MILLION

$28 TRILLION
Healthy women, Healthy Economies

Barriers to women’s health and well-being impede their ability to join, thrive, and rise in their communities, and live better lives.

65%\(^1\) Non-communicable diseases are the leading cause of death for women and account for an estimate 65 percent of all female deaths worldwide.

x6\(^2\) Women who have caregiving responsibilities are six times as likely to suffer from depression or anxiety compared to women without caregiving responsibilities.

x2–3\(^3\) Multiple sclerosis impacts two to three times more women than men.

x2\(^6\) Twice as many women who have heart attacks die within one year, compared to men.

2nd\(^5\) Cancer is the second leading cause of death among women. One in seven women in the Americas, Europe and the Western Pacific regions dies every year from cancer.

x5–8\(^4\) Thyroid diseases impact five to eight times more women than men.
Healthy Women, Healthy Economies is a global initiative that unleashes the economic power of women by bringing governments, employers and other interested stakeholders together to improve women’s health so women, and by extension their families, can join, thrive, rise in their communities, and live better lives.

We do this by supporting research to quantify the issue, forming meaningful collaborations to advocate for change, and leading by example in three key policy areas:

**Health Access & Awareness:**
Tackle non-communicable and communicable diseases that disproportionately impact women and prevent them from participating and succeeding in the workforce.

**Work/Life Integration:**
Support women who work – both paid and unpaid work – and create supportive work environments and health systems that can help women achieve greater work-life integration and improve their overall health and well-being.

**Empowerment & Parity:**
Work with public and private organizations to support creating equitable work environments where talented women and men can thrive and rise, without sacrificing their health.
Internal Walk the Talk: Women in Leadership Action Team

Women in Leadership Global Action Team:
Healthy Women, Healthy Economies raised issue of gender parity at Merck, we are now ready to “walk the talk”

Merck Healthcare: People & Leadership Priority
Drive gender balance in leadership positions

Project Goals: Merck Healthcare
- Representation, engagement & retention rates at role 4+ will be the same for women & men
- An inclusive culture that supports women and ensures their continued engagement
- 50-50 gender balance in Role 4+ by 2023
Merck’s Commitment to Healthy Women, Healthy Economies

We have adopted the mission of Healthy Women, Healthy Economies and are putting action behind our expanded commitment to the program by:

**Supporting research** to quantify the issue linking women’s health and well-being to their economic prosperity

**Forming meaningful collaborations** to advocate for change.

**Living the mission** through our internal corporate commitments to bring Healthy Women, Healthy Economies to life for our employees
Mobilizing Oncology Carers Globally: Unique Challenges Facing Women

Soraya Araújo, Merck Brazil, Government Affairs and Policy & Social Responsibility
World Cancer Congress
October 2, 2018
Healthy Women, Healthy Economies & Embracing Carers synergistically address important societal topics

- Unmet needs of caregivers in healthcare systems
- Aging societies
- Long term chronic care needs
- Adverse health outcomes associated with providing unpaid caregiving
- Health barriers to economic participation
- Women’s empowerment and leadership
- Supporting the family’s ability to increase prosperity

Embracing Carers™ is supported by Merck
Embracing Carers

Ricardo Blum, M.D., Medical Director
Merck Brazil
Launched in October of 2017, Embracing Carers™ is a movement developed to highlight the unmet needs of unpaid carers on a global and country level; empowering them to advocate for their own health and well-being, and driving a call to action for support worldwide.
Embracing Carers™ is advised and supported by a first-of-its-kind Carer Collaborative, who serve as ambassadors of the initiative.

- Guide activities
- Identify strategic opportunities
- Share information

Collective reach to >100M Carers around the world
Embracing Carers™ recognizes the need to shine a spotlight on the challenges carers face and strives to provide solutions.

**Stakeholders**
Support capacity building and collaboration of organizations to support caregiver initiatives

**Awareness**
Increase awareness and the global discussion of carers through by activating and highlighting the unmet needs of carers through media and digital platforms

**Policy**
Drive policy focus, legislative action and visibility among policy makers, governments and international public health organizations

**Health Care Systems**
Create innovative opportunities to integrate caregiver support and resources throughout the spectrum of care
The inaugural year of Embracing Carers™ focused on the building, launch and implementation of the global initiative.

1 Caregiver Global Survey
- Research to highlight challenges and opportunities across all key markets and inform initiative development via Censuswide survey

2 Creation of Resources
- Launch of www.EmbracingCarers.com, video, whitepaper, infographics, press releases, social media toolkits

3 Global / Local Launches
- Release of whitepaper, communication to patient advocacy organizations, media outreach, and policy efforts in the US, Australia, and EU5*
International Carer Survey Findings

Highlighting the impact caring for others has on one’s health, finances, employment and emotional well-being

CENSUS-WIDE SURVEY:
- 3,516 unpaid carers
- 18-75 years
- Australia, France, Germany, Italy, Spain, UK, US
- Online survey conducted between 27 July and 8 August, 2017

47% of unpaid caregivers have feelings of depression.

Almost 3 in 10 unpaid caregivers feel their role as a caregiver is unrecognized by their healthcare system.

55% of unpaid caregivers feel that their physical health has suffered.

30% of unpaid caregivers feel that their role as a caregiver has put pressure on their financial situation.
2018 Expansion
Embracing Carers

2018 Brazil Survey Results

FEMAMA Founder and UICC Board Member
Maira Caleffi, M.D.
About FEMAMA

Brazilian NGO focused on Breast Cancer Patient Advocacy

FIGHTS FOR

- mortality due to breast cancer in Brazil
- access to diagnosis and treatment of breast cancer for people

Single Agenda Networking

74 NGOs
18 States + Federal District

To raise awareness, to debate and to promote actions that address the needs of caregivers

To create connections and implementing practical solutions to support them
2018 Carer Survey Findings Brazil

Survey conducted in collaboration with four patient advocacy organizations across Brazil

CENSUS-WIDE SURVEY:
- 578 unpaid carers
- 18-75 years
- Brazil
- Online survey conducted between 27 July and 8 August, 2018

46% dos cuidadores não profissionais muitas vezes não têm tempo para agendare ou comparecer às suas próprias consultas médicas.

Junte-se ao Movimento Embracing Carers™

61% dos cuidadores afirmam precisar de cuidados médicos por conta de sua saúde mental.

Junte-se ao Movimento Embracing Carers™

www.embracingcarers.com

O Embracing Carers™ é apoiado pela Merck.

Embracing Carers™ is supported by Merck
Embracing Carers Brazil
Carer Survey Topline Results

- 92% of informal carers feel supported by their family
- 46% of informal carers living in urban areas care for their parent
- Over half (57%) of informal carers say their relationship with their family is not affected by their role as a carer

- 60% of informal carers don’t feel supported by the government
- 68% of informal carers feel supported by their local health authority/service
- 30% of informal carers feel their role is unrecognised by their healthcare system

- 58% of informal carers find their carer role rewarding, yet challenging
- Over half (55%) of informal carers feel satisfied that they are providing a better quality of life for the person they care
- Over half (53%) of informal carers have developed a more positive attitude to life since being a carer

Positive family support

Government support

Local health authority support

Carers somewhat recognised

Rewarding yet challenging

Sense of personal satisfaction and improving quality of life for those they care for
• Nearly half (46%) of informal carers often don’t have time to book or attend medical appointments for themselves
• 44% of informal carers say they put the health of the person they care for ahead of their own
• 61% of informal carers say they need medical care for their mental health

• 53% of informal carers say they feel tired most of the time
• Almost half (46%) of informal carers take care of their parents and those with an average age between 45-55 spend 24 hours a week caring for the person they care for

Carers not caring for themselves
Feeling depression
Tired most of the time
Caring impacts on people’s time
"Welcome to my crazy, wonderful world of living".
Join the Embracing Carers™ Movement

#EmbracingCarers
#CareForACarer

1. Identify a carer you know would appreciate receiving acknowledgment
2. Show you care with a message of support
3. Post on social media to help raise awareness
Thank You