

CAREGIVING IN THE PORTUGUESE SPEAKING COMMUNITY

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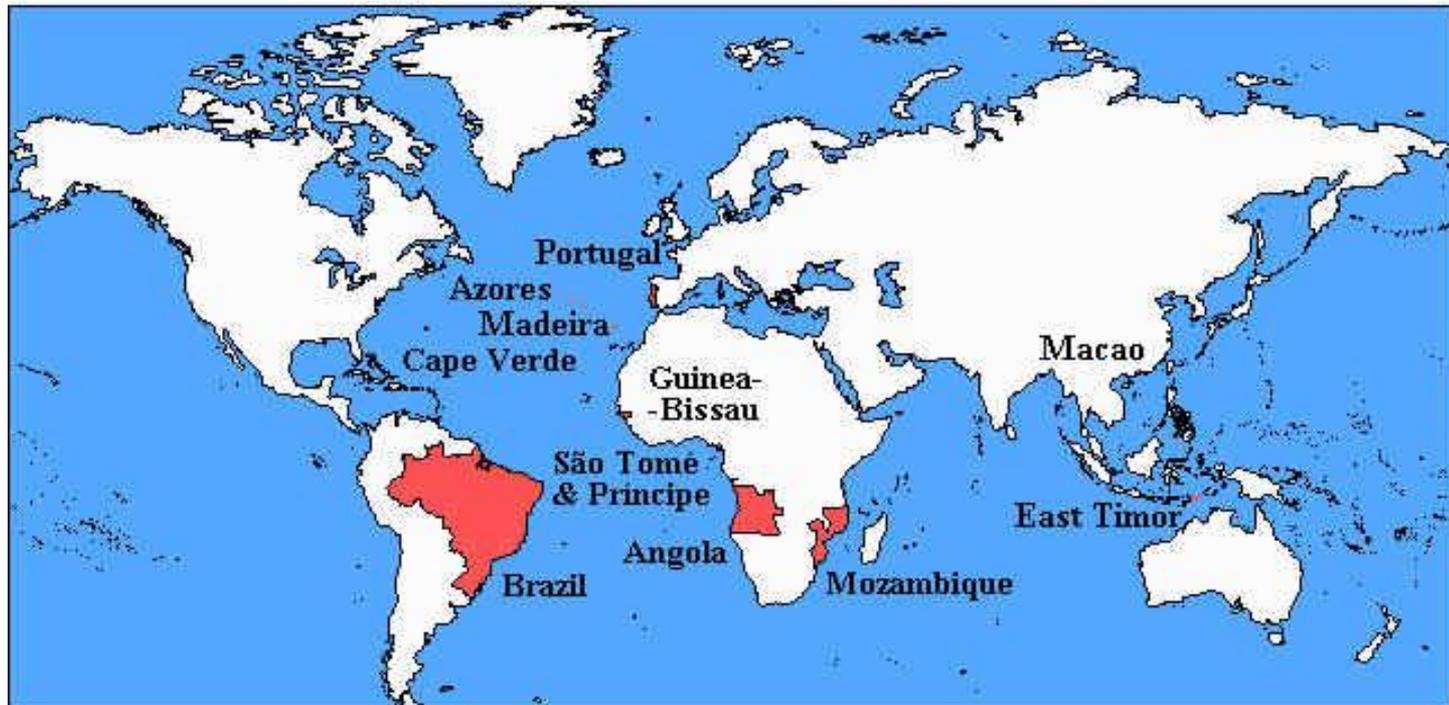
FACTORS THAT MAY IMPACT CAREGIVERS' ACCESS TO SERVICES AND COPING MECHANISMS

- Birth Place - country, rural/urban
- Time of immigration
- Religious and social beliefs
- Education/literacy/English language skills
- Family support/dynamics



A DIVERSE COMMUNITY

- Portugal- mainland and the Azores and Madeira
- Brazil
- Cape Verde
- Angola
- Mozambique
- Other



SOME BACKGROUND...

- Immigration waves : 53 to late 70's (mostly rural, and from the Islands)
- Slow immigration from the 90's on
- Parents came in to support children (e.g. baby sitting)
- Cultural/social/religious values transmitted to new generations - strong sense of responsibility for aging parents, expectation that daughters look after them; “it is my cross to bare”, “never abandon me”, “what would the neighbours say”
- Stress and frustration for families balancing between community old values and new realities



THE COMMUNITY TODAY

- An aging community
- Caregivers in work force, with own families, often with 2 sets of aging parents
- Parents stay in old neighbourhood, children moved
- 2nd & 3rd generations less/not fluent in Portuguese + reduced immigration= less Portuguese speaking workers (e.g. Social Workers, PSWs)
- Competition from Hospitals and LTC for SWs, PSWs, = increased difficulty hiring language specific workers by community sector
- Immigrants from other Portuguese speaking countries help minimize problem



THEN AND NOW

- 25 years ago St. Chris opened its Adult Day Program –initially offered in English and Portuguese, (now also Cantonese, Italian, Vietnamese)
- Conducted an outreach / educational campaign with support of ethnic media (TV, Radio, newspapers), churches, a few physicians
- Study: many of the concerns addressed then still exist today but improvement has been made



CONCERNS

- Caregivers feel enormous burden, including physical, emotional and financial stress —similar to most cultural and mainstream
- Family dysfunction often aggravated by caregiving responsibilities
- Primary caregiver often report lack of family support in caring and decision making (feel alone)
- Difficulty accepting services... Not wanting “strangers in and out”, too confusing, too stressful



...CONCERNS

- Lack of worker consistency, language
- Transportation
- Clients seldom referred to services by their family physicians
- Self referred (families "diagnose" based on their own knowledge of AD).
- Lack of clear communication between physicians and patient/family (even when speaking same language)



WHAT HAS IMPROVED

- Increased services (e.g. ADP extended hours)
- ADP priority for Transportation Programs, TC LHIN
- Increased awareness/knowledge of AD = decreased the stigma and myths attached to AD
- Closer collaboration between CSS and CCAC (Enhanced ADP), the Alzheimer Society and other providers (BSO)
- Increased of innovative programs provided by the Alzheimer Society (ipod project)
- Community Access and Navigation Program – CNAP
- Carers Program (being piloted in the community)



ROOM FOR IMPROVEMENT

- Continuum of services designed to meet caregivers' needs at different stages of the disease.
- Increase of affordable services – e.g. in home respite limited and/or for a fee
- More Primary Care involved and informed
- Carers program – expansion of program in the community
- On going education –Media (always ready to partner) , Forums



HATS FORUMS CAREGIVER TO CAREGIVER



Health Action Theatre by Seniors



WHAT CAREGIVERS SAY

About the ADP

- “I know that my Dad is in a great and safe place while I’m at work. It give me peace of mind.”
- “It’s good to have people that speak my Mom’s language and she has people of her generation to be with”
- “The hours work well. My Dad spends 6-7 hours with good people that make him feel comfortable”
- “My Dad can stay in his own home. This is important for both of us.”
- “ Provides a socializing environment for my Mom and a rest for my sister”



WHAT CAREGIVERS SAY...

...and about the **Carers Program**:

I'm doing it
for both of us.

It gives me some
comfort to know that
other people are going
through the same, I
don't feel so alone.

I wish more men
would participate
these groups so
they can better
help their wives.

This "class" has taught
me a lot and I feel that I
can understand my
wife's behaviours better.



ABOUT THE CARERS GROUP...

Staff 's comment : I observed that they developed a terrific bonding amongst them and a caring that goes on. They look out for each other and worry about one another. They all come out of the sessions laughing and joking with one another. It is great to see the smiles on their faces.

