



Cancer survivorship needs in Mexico

**International perspectives on post-treatment
World Cancer Congress**

UICC Global Cancer Control

Melbourne, Australia, December 4, 2014

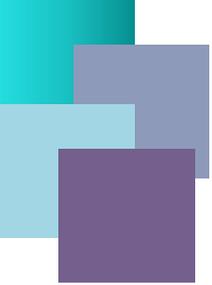
Dra. Felicia Marie Knaul

Harvard Global Equity Initiative and Harvard Medical School

Fundación Mexicana para la Salud y Tómatelo a Pecho

With Hector Arreola, María C. Gonzalez, Harper Hubbling,

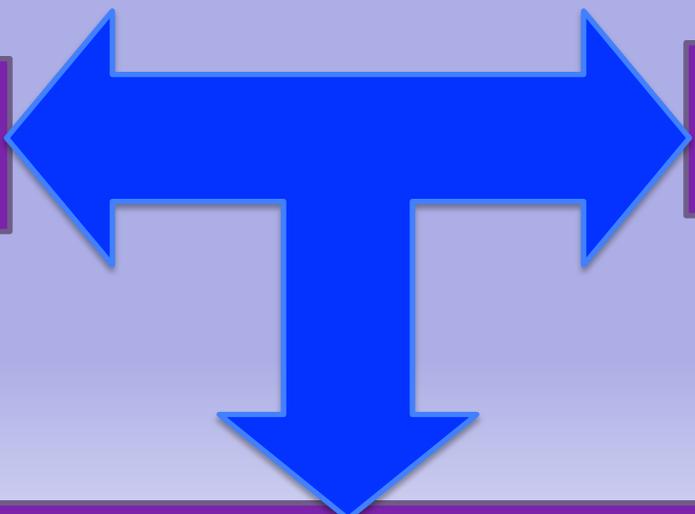
Alessandra Durstine



Duality: evidence and advocacy

**Evidence-based
advocacy**

**Advocacy-inspired
evidence**

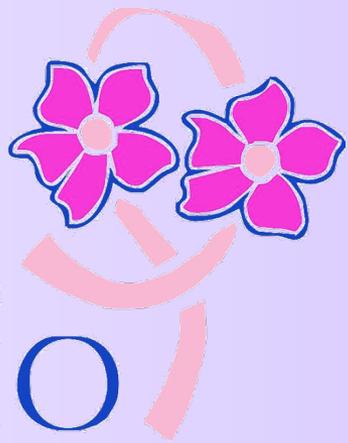


**Action:
projects, programs, policies**





CÁNCER DE MAMA
TÓMATELO
A PECHO



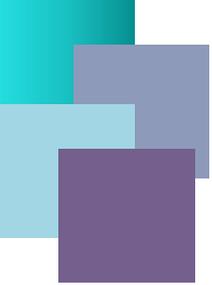
Champions:

Drew G. Faust
President of Harvard
University
BC 25 years ago



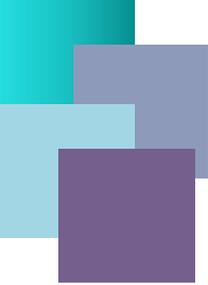
Nobel Amartya Sen,
Cancer survivor diagnosed in
India 65 years ago





Outline

- 1. UHC and survivorship*
2. Mexico *Seguro Popular* and coverage of cancer
3. Results of Qualitative Survivorship studies Mexico
4. Policy recommendations



Worldwide wave to reform health systems in the quest for UHC in many countries

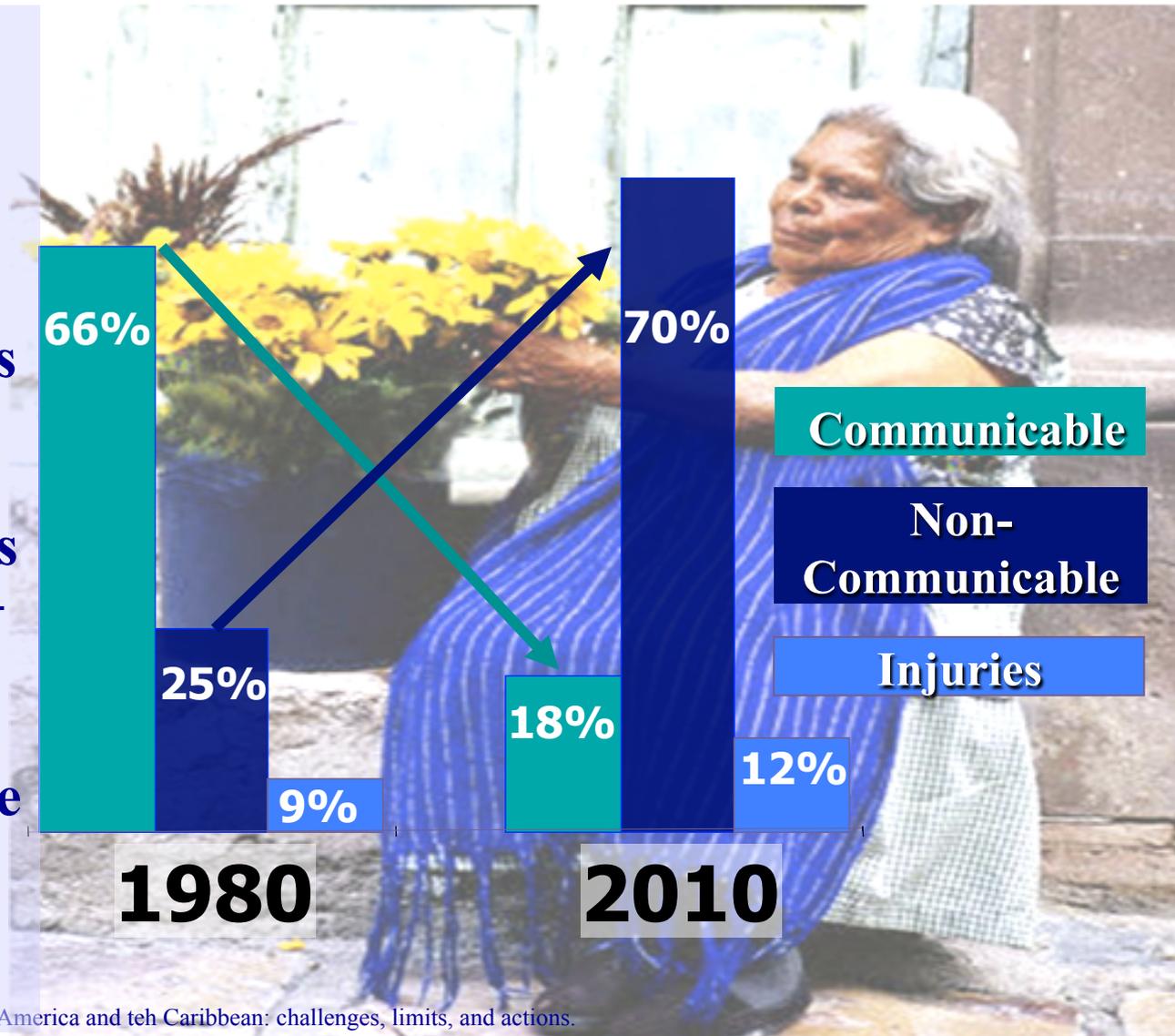
Examples:

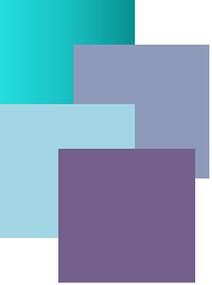
- *Mexico*
- *Brazil*
- *Colombia*
- *Chile*
- *Dominican Republic*
- *El Salvador*
- *Peru*
- *South Africa*
- *China*
- *USA*

Yet...often in the context of rapid, profound, polarized and complex epidemiological transition while battling fragmented health systems

In Latin America and the Caribbean, demographic and epidemiologic transitions have been rapid and profound

- © In just over 40 years, LAC will achieve the aging rates that most European countries took over two centuries to reach.
- © Life expectancy has increased from 30+ in 1920, to 75+ today
- © In a very short time period, the causes of death have reversed

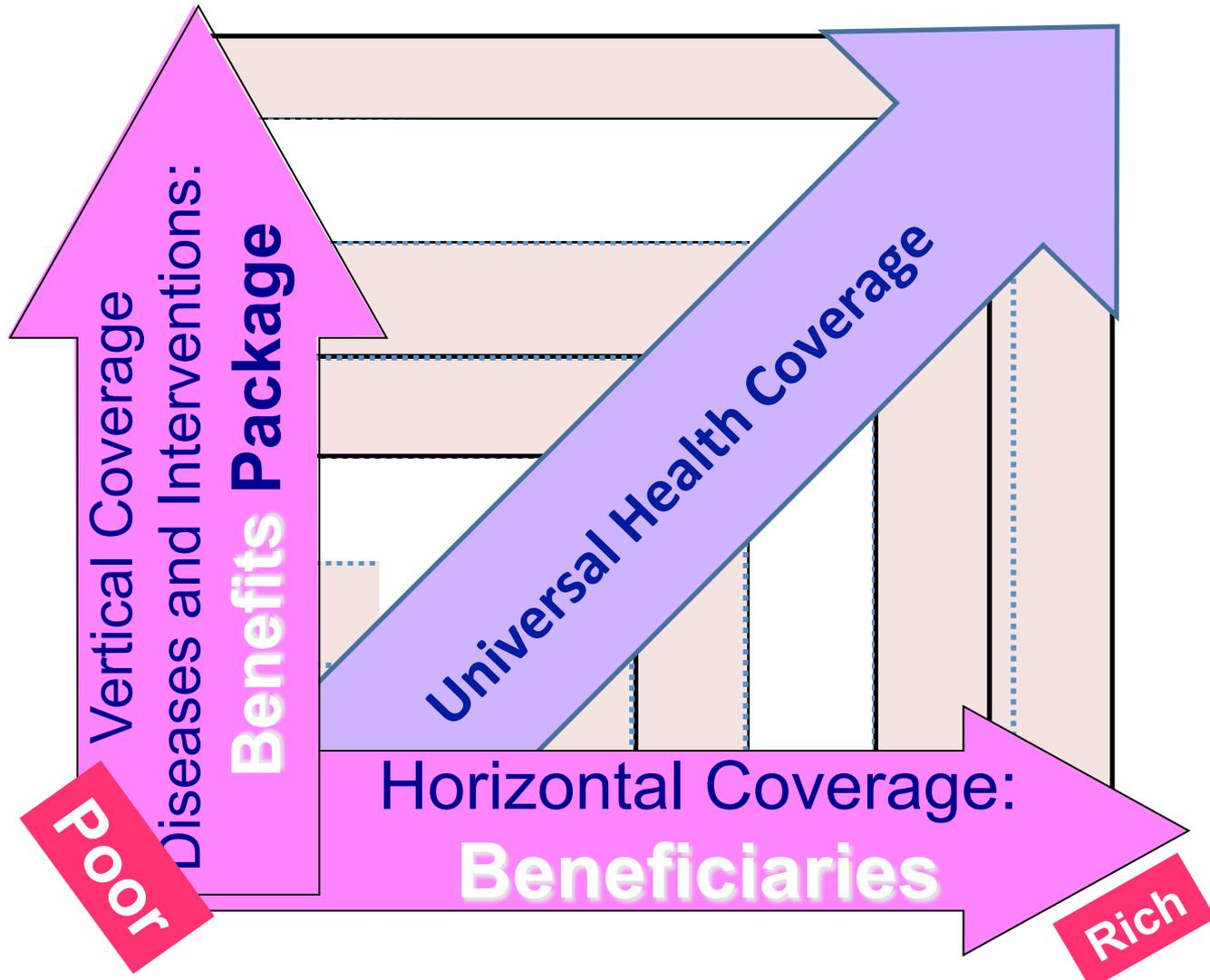


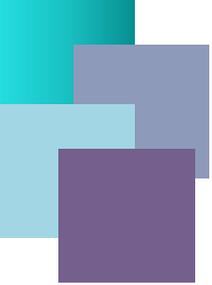


Universal Health Coverage (UHC)

All people should obtain needed health services – prevention, promotion, treatment, rehabilitation, and palliative care—without risking economic hardship or impoverishment
(WHO, WHR 2013).

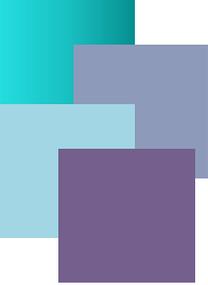
Expansion of Coverage





Effective Universal Health Coverage (*eUHC*)

- Beneficiaries: Vulnerable groups
- Benefits: an *explicitly defined* package
- Financial protection
- *Integrated across the life cycle: diseases and people*



An *effective* UHC response to chronic illness must integrate interventions along the

Continuum of disease:

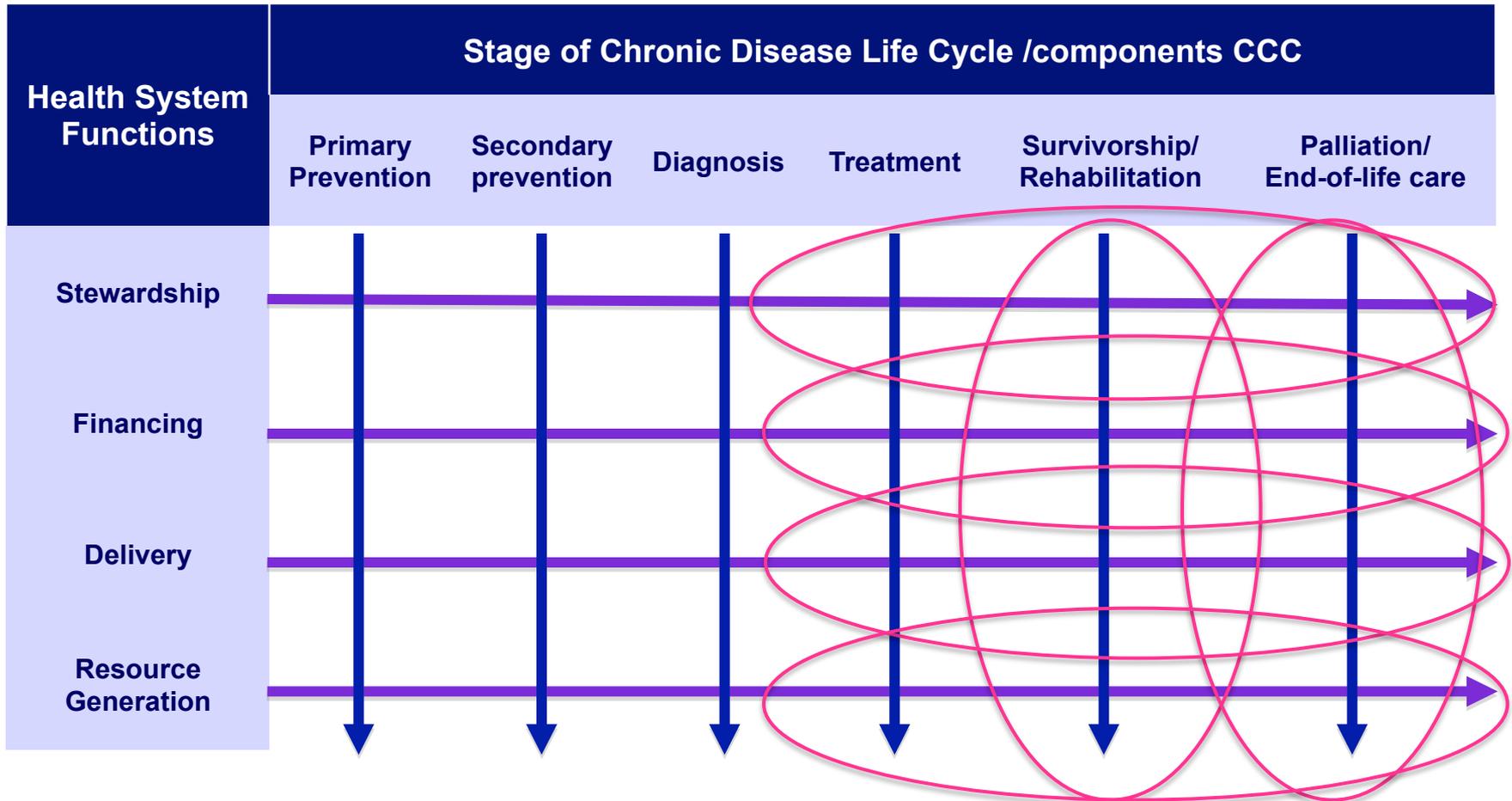
- 1. Primary prevention**
- 2. Early detection**
- 3. Diagnosis**
- 4. Treatment**
- 5. Survivorship**
- 6. Palliative care**

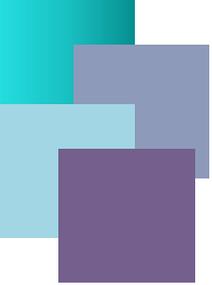
....As well each

Health system function

- 1. Stewardship**
- 2. Financing**
- 3. Delivery**
- 4. Resource generation**

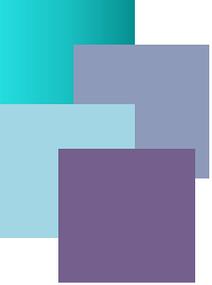
eUHC requires an integrated response along the continuum of care and within each core health system function





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and coverage of cancer***
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Cancer Care Financing Innovations

Integrate CCC into national insurance and social security programs to beginning with cancers of women and children:

ℓ **Mexico, Colombia, Dominican Republic, Peru**

ℓ **China, India, Taiwan**

ℓ **Rwanda, Kenya**

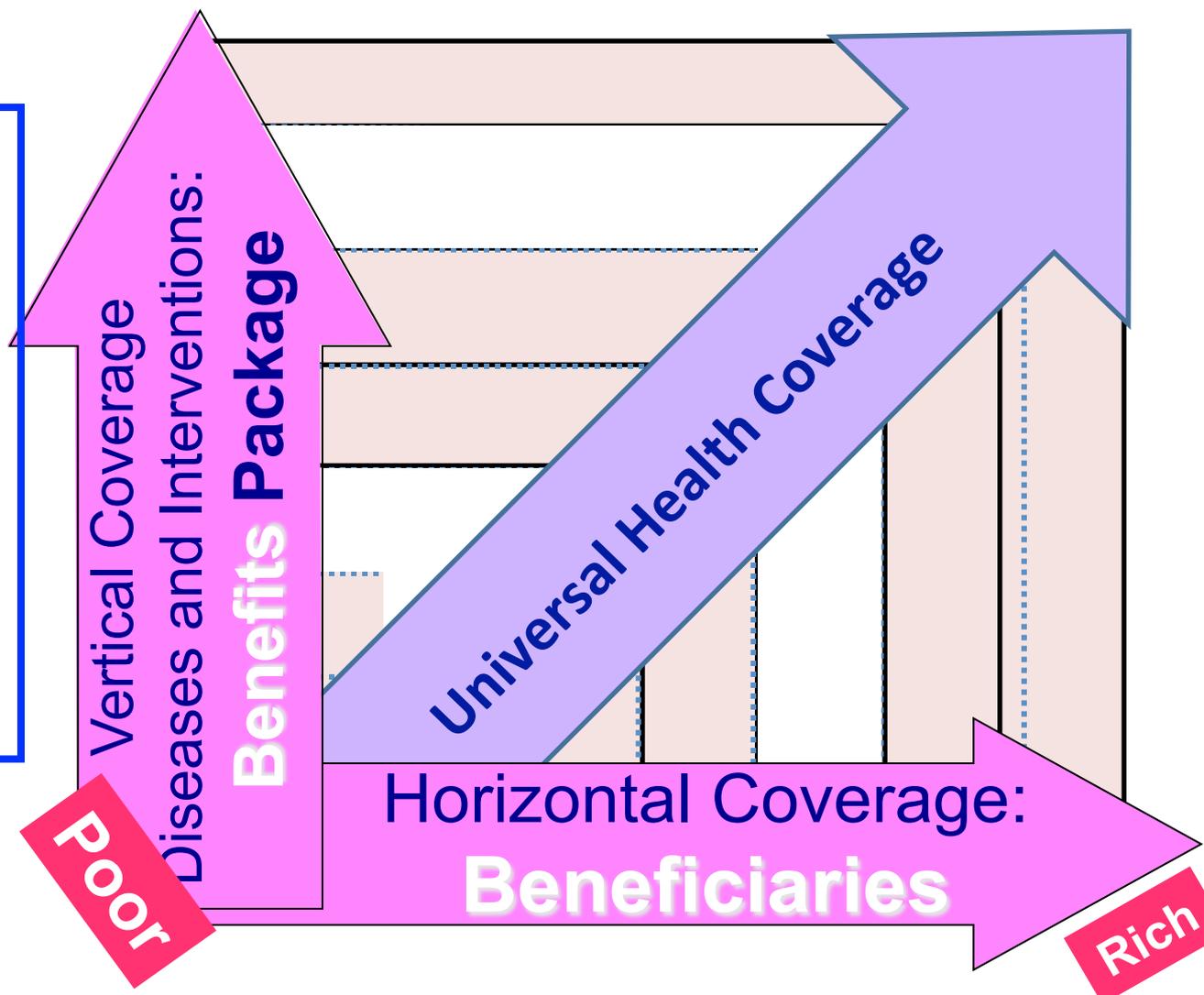
Mexico's 2003: major health reform created *Seguro Popular*

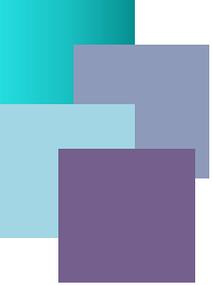
Affiliation:

- 2004: 6.5 m
- 2013: 55.3 m

Benefit package:

- 2004: 113
- 2013: 284+59





Key aspect of *Seguro Popular*:
diagonal, financial protection for
catastrophic illness

- ⌘ Accelerated, universal, vertical coverage by disease with an effective package of interventions
 - ⌘ 2004/6: HIV/AIDS, cervical cancer, ALL in children
 - ⌘ 2007: All pediatric cancers; Breast cancer
 - ⌘ 2011: Testicular and Prostate cancer and NHL
 - ⌘ 2012: Ovarian and colorectal cancer

Seguro Popular and cancer: Evidence of impact

ℓ Childhood cancers

ℓ adherence to treatment:
70% to 95%

ℓ Breast cancer

ℓ INCAN

ℓ 2005: 200/600

ℓ 2010: 10/900

**The human faces:
Guillermina Avila
Abish Romero**



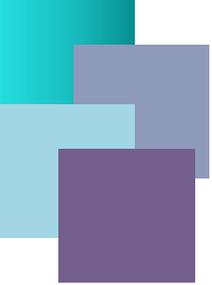
Effective financial coverage of a chronic disease: breast cancer

Cancer Control-Care continuum



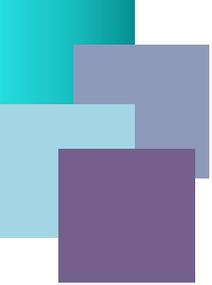
Mexico: Large and exemplary investment in financial protection for breast cancer prevention and treatment, *yet.....a low survival rate.*

Strengthen early detection, survivorship and palliation:
diagonalize delivery



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Study design1:

*25 young breast cancer survivors interviewed at
INCAN, Mexico City, 2014*

Interviews: One-on-one, semi-structured, 30-60 minutes, audio-recorded
Topics: psychological, social, employment, religion, body image, fertility

“Survivors:” ≥ 5 years since diagnosis

“Young:” Diagnosed at ≤ 40 years old

Clinical characteristics

Average age at diagnosis	36
Average years of Survivorship	7
Mastectomy	84%
Reconstruction	24%

Demographic characteristics

Residence	44% DF
Average monthly income (pesos)	4290
Average years of formal education	11
Marital Status	16% Single

Lasting survivorship challenges for young women:

Employment discrimination

“...“... a person with cancer, now no one what to employ them. Because we are no longer useful (no servimos). Yes, yes discrimination does happen..”

“I like to speak the truth when I go to ask for a job. I tell them, ‘I had cancer and I have to go to therapy or appointments,’ and they tell me, ‘we don’t allow absences,’ ‘Ok. Perfect. Thank you see you later.’”

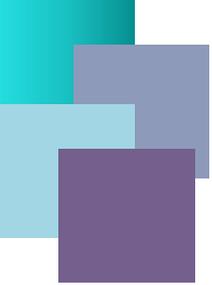
Loss of social networks

“I’ve drawn back a lot. Well I think this feeling.. Many times those who you think are your friends because well, you’ve gotten along well, but they look at me poorly and distance themselves”

Body image – changes w time

“They always tell me, ‘dress up, make yourself up, do this,’ and I say, ‘for what? For what now?’ I have become.. Like depressed. Like.. not depression, like I told you, a lack of interest.”

“...the first years did not affect me..... I did not care... now it is affecting me. For a year, I have been seeing myself and not accepting myself, it is very hard for me to accept myself as a I now am..”



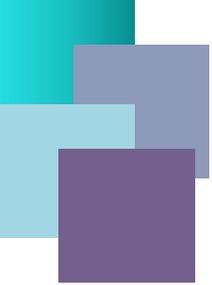
Survivorship care for young patients:

Need for longitudinal psych follow up

“ “... the disease has not done anything to me really it was a small tumor, they took it out and that was it. But....the fear, the family, my morale, the children – the damage is terrible.... Healthy we [the patients] now are. But our minds, how are they left? The psychological, how it left?” ”

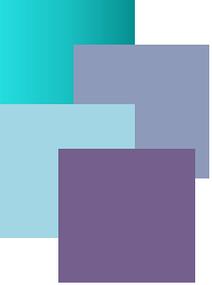
Psychosocial barriers to adherence during follow up

“And he [the psychologist] told me, ‘you have to learn to live with this. Learn that all of your life you are going to have to come to the hospital, all of your life, see sick people. It is a form of life.’ And I said, ‘well, it is true,’ because I want to forget this but, I want.. Well yea I’m always going to see it, end of story, right?”



Principal findings for young women

1. Fear/uncertainty surrounding fertility
2. Body image perception challenges
3. Employment discrimination and its impact
4. Loss of social networks
5. Unmet primary and psych care needs



Study design 2:

Cancers:

- Breast (24 patients)
- Cervical, Prostate, Leukemia in children

Service providers:

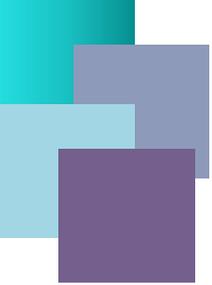
- 4 focus groups w nurses (total 27)
- in depth interviews with oncologists and general physicians.

México: Nuevo Leon, Puebla, Morelos and Mexico City

Data collection: 2014

Interviews: 1:1, semi-structured, 30-60 minutes, audio-recorded

Topics: psychological, social, employment, coping mechanisms, family support, body image, fertility



Understanding survivorship: service providers versus patients

Survivorship



Service providers:

A “survivor” is a person who has a disease that puts their life at risk and is alive 5 years after diagnosis

Women living with BC:

The “survivor” is “a person who is free of the tumor”” it is when the doctor declares that you are in remission”

Survivorship as discussed and described

By service providers:

- ✓ There is no formal, integrated follow up program for the patients after they complete their “acute” treatment.
- ✓ Follow up to be sure that the patient is “free of tumor – disease free”. The secondary effects “secuelas” of treatment should not be treated in third level care.
- ✓ Psychosocial needs are recognized by the provider, but they indicate that these are the responsibility of other levels of care and should not be considered part of the care they have to offer in specialty hospitals.

“The term “survivor (ship) es colloquial vocabulary and does not translate into medical vocabulary which is what should be used. For us, there are no patients in survivorship but rather patients in remission, recurring, or in palliative care”.

MD-3 Mty.

..”it is the patient who is in remission from cancer, that her cancer is not advancing....that it will be... 5-10 years depending on the type of cancer.”

MD-1 Mty

“...a patient who had a diagnosis of breast cancer and received treatment and is currently under surveillance”.

MD-4 Mty

Survivorship as discussed and described by women with breast cancer:

✓ It is not a concept that spontaneously emerged from discussion with patients.

✓ Survivorship is linked mainly to two issues:

❖ Children. This is why they “fight” against the disease and maintain themselves “alive”.

❖ Spirituality: They are being tested by G-d.

... “I felt myself to be a survivor. When they operated on me, with the hand of God, I will survive and move ahead with my life”...

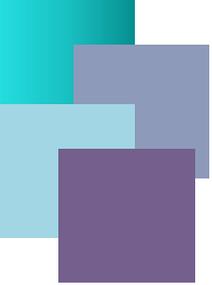
M- 4 CM Mty

...“It is a test of God. I am alive by the grace of God. And if God left me on this earth it is because I have something more to do...”.

M- 2 CM Mty

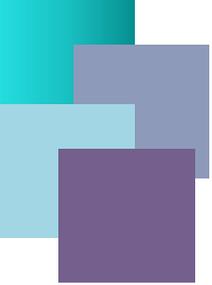
...”It was a beautiful moment when the doctor told me: “ there is good news, you wont be receiving any more RT, but you will have to take a little pill for 5 years”. I asked “why 5 years?”, he said be it is scientifically proven that the patient who takes the pill for 5 years, ,well that is it..... After those 5 years you can say “I did it”, or in other words, I am now free”.

M. 7 CMMt



Summary:

- Survivorship care is largely absent in LMICs and strategies must be designed and implemented to respond to patient needs.
- In Latin America survivorship care will become increasingly needed and challenging as epidemiological transition proceeds and reform increases health care coverage and access.
- Survivorship as a stage of the cycle of disease is context specific and at the same time unrecognized.
- Survivorship care must be integrated into UHC and each health system function (stewardship, financing, delivery, capacity building)



Policy Recommendations

- Establish multidisciplinary medical care provider teams
- Include treatments and services for long-term care of cancer patient side effects in insurance systems and the covered package of care
- Establish clinical practice guidelines for survivorship treatment and include in overall official guidelines
- Promote patient navigation systems for ongoing care for cancer survivors.
- Educate policy-makers about providing long-term care and addressing quality-of-life issues including legal protection
- **Capacity building for physicians, nurses, other health providers and promoters at the primary level of care**



Long term cancer survivorship needs: The qualitative case of Mexico

International perspectives on post-treatment survivors
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