

# Young at Breast!

Barbara Clow, Kristin MacLellan, and Kathy Petite

Atlantic Centre of Excellence for Women's Health, Dalhousie University, Halifax, Nova Scotia

www.acewh.dal.ca

## 1. Introduction

Young women with breast cancer comprise a diverse population under-represented in research, policy, and programming. Though younger women represent a comparatively small proportion of breast cancer patients, they often face poorer prognoses and personal issues that are specific to their age and stage in life. Although researchers and clinicians are paying attention to the experiences and needs of young women with breast cancer, there is a disturbing lack of consensus about what constitutes a “young” woman in this context. Some researchers and clinicians define “young” in terms of chronological age, others refer to life stages, including the child-bearing years and premenopausal status, and still others simply do not define the category. This lack of consensus and clarity is exceedingly problematic when exploring the health care needs of women diagnosed with breast cancer.

*I get really angry when I see advertisements about detecting breast cancer and all the women are old. It makes you think you can't get breast cancer [when you are young] and it's just not true.*



## 2. Incidence

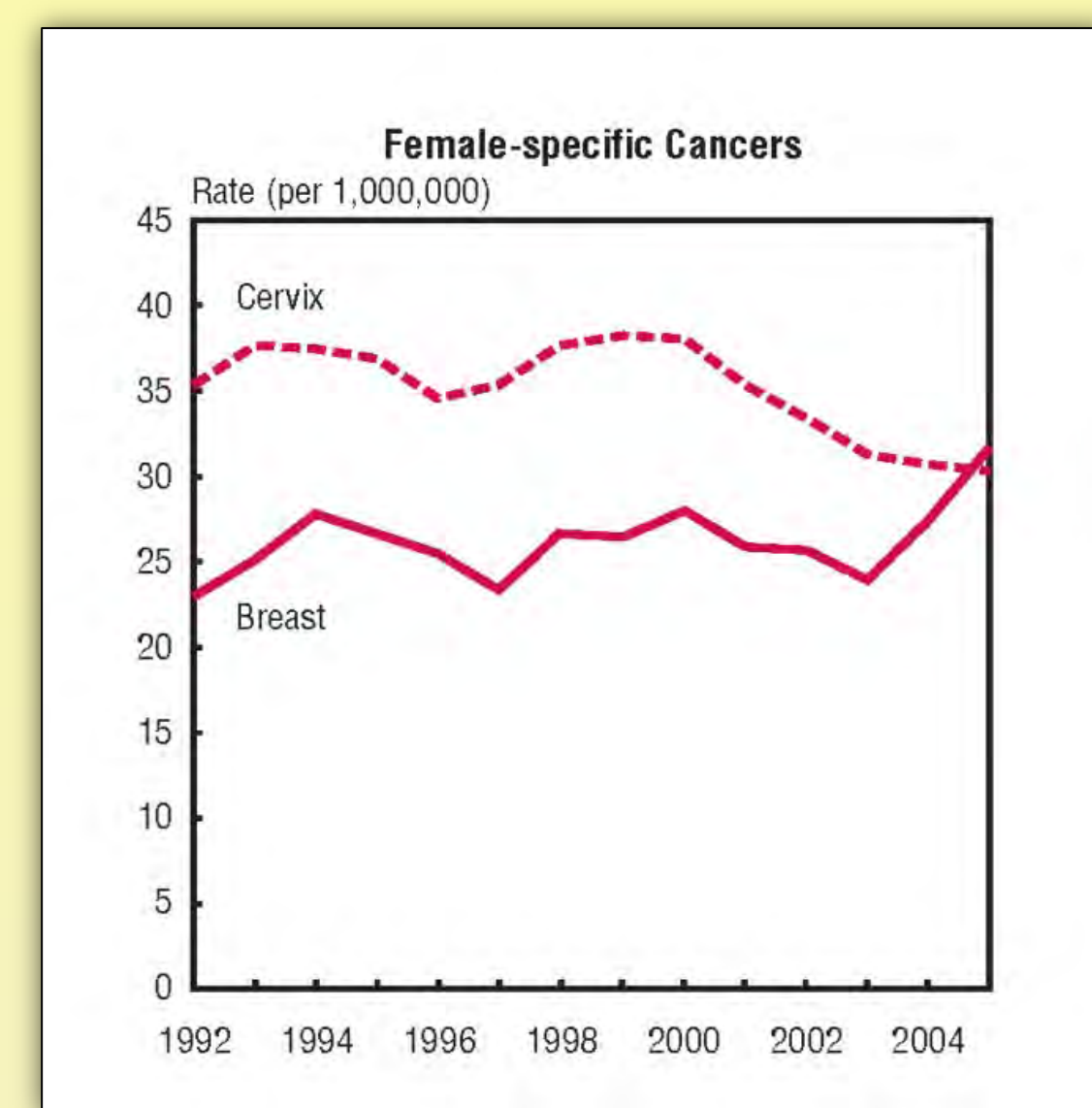


Figure 1. Age-standardized breast cancer incidence rates in adolescents and young adults in Canada, 1992-2005. Source: Canadian Cancer Statistics, 2009

Breast cancer survival rates are improving for all age groups, with the result that more and more women are living through various life stages after a cancer diagnosis.

Since 1992, breast cancer rates have increased among premenopausal women. Some researchers hypothesize the increase is related to more women waiting until later in life to have children.

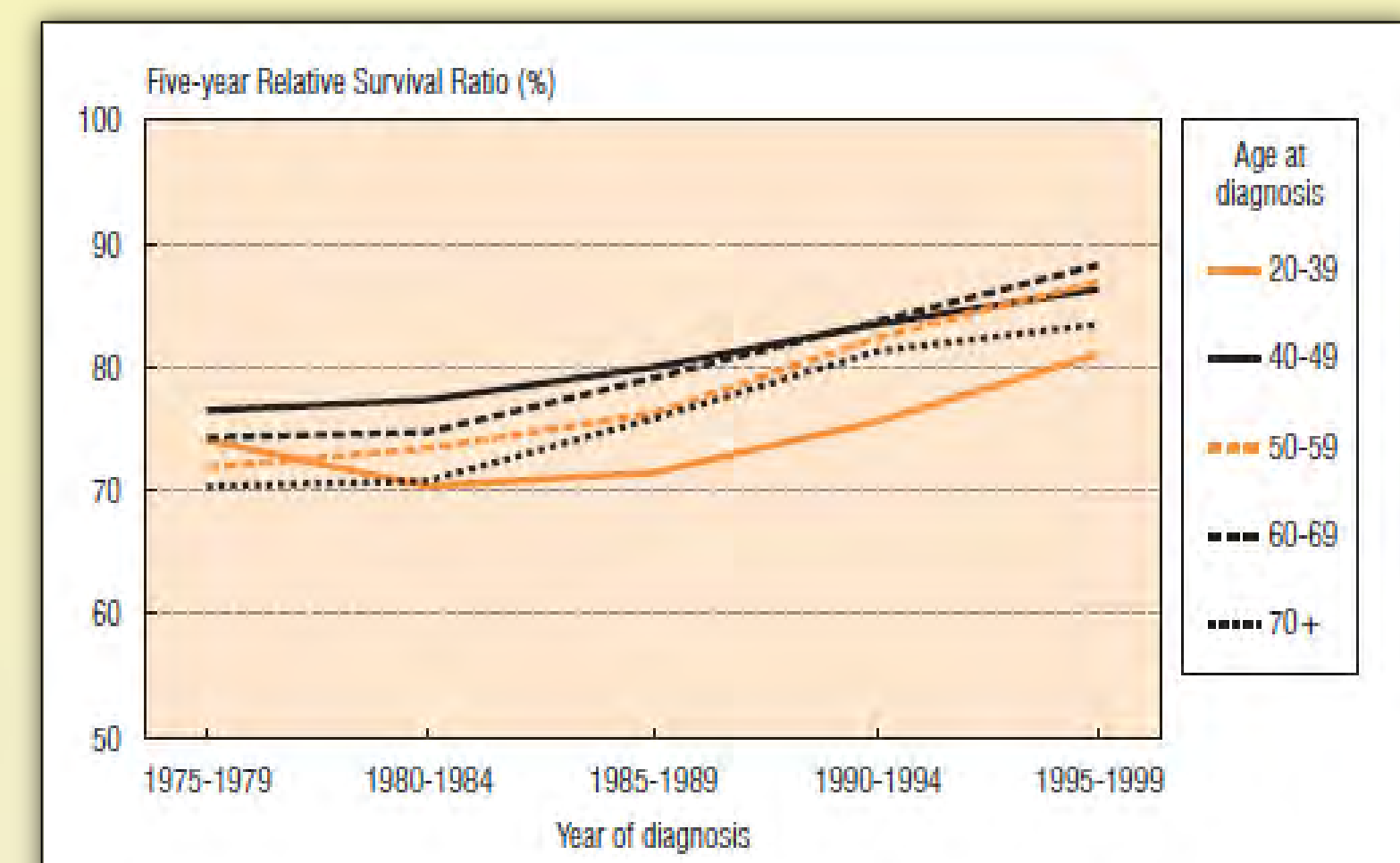


Figure 2. Five-year survival ratio by age group over time. Source: Canadian Cancer Statistics, 2007

## 3. Research

*[I] was waiting for the radiotherapy to start. In the meantime my mum had the stroke. So I was spending my life running after her.... it was like trying to walk up a hill. I went to the hospital with her but I really didn't have time to think about myself, it's just a case of getting her sorted out and then getting her into rehab and doing all those things that you have to do.*

Among practitioners and civil society organizations, there is a growing recognition that the needs of young women with breast cancer may be different from those of older women, yet services tailored to young women are limited or absent.

In order to better understand the state of knowledge about young women with breast cancer, the Atlantic Centre of Excellence for Women's Health undertook an extensive literature review of peer-reviewed and grey literature.



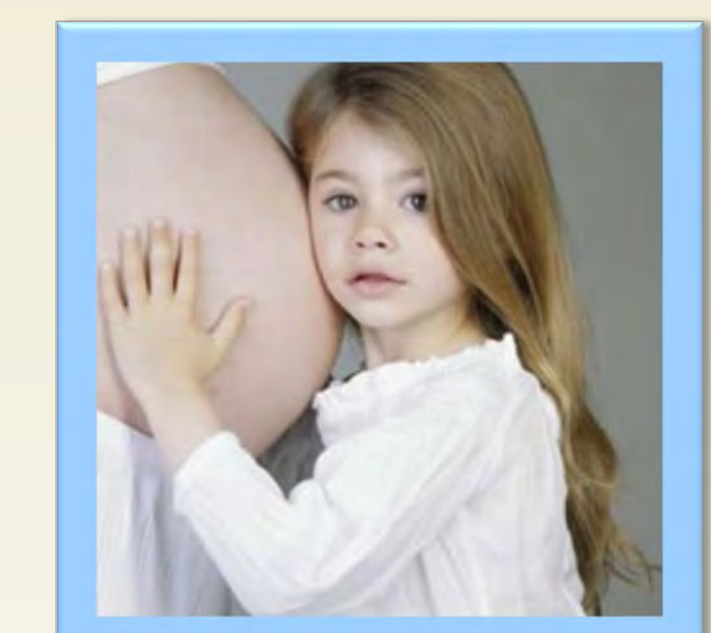
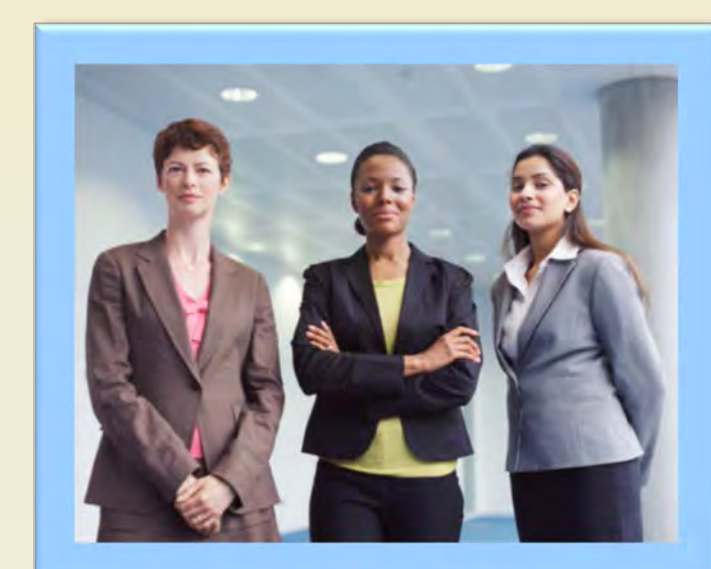
## 4. Defining “Young”

In the literature, youth is considered an important diagnostic and treatment category for women with breast cancer. Researchers and clinicians tend to use two main ways of defining “young”: physiology/chronology and life stage.

**Physiology/Chronology:** In some studies, women who fall into specific age groups – such as under 35, 45 or 55 – and women who are premenopausal are considered “young”

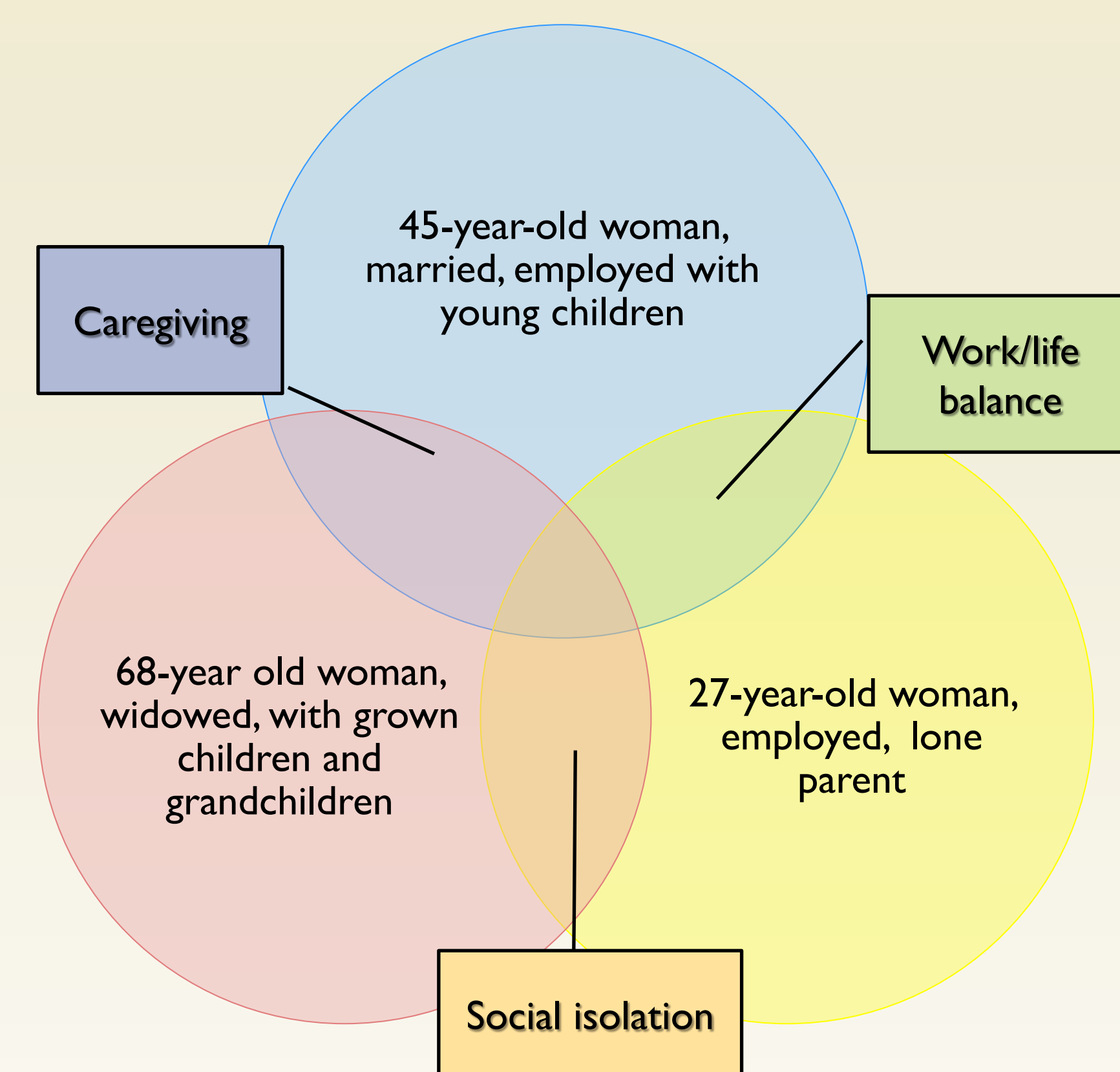
**Life Stage:** Other literature focuses on life stage. Women with breast cancer are considered “young” if they are in the midst of acquiring education, building careers and relationships, or are in the prime reproductive years.

Often these definitions overlap but there is no consensus about how best to define “young” when it comes to breast cancer. In fact, some articles offer no definition at all.



*My daughter is five. She has been amazing through all of this. She is just a sweet little thing. I wonder if I will be there to watch her grow and that scares the living crap out of me. I can't imagine not watching her graduate, get married, go to college, get her first job, have her first boyfriend. I just hope so much that I am allowed to see all those things first hand.*

## 5. Discussion



Categorizing women by age or life stage may make statistical analyses easier, but it is also problematic.

On the one hand, if we lump together all women who are under 50 when diagnosed with breast cancer and label them as “young”, we risk designing supports that do not meet the needs of different groups of women.

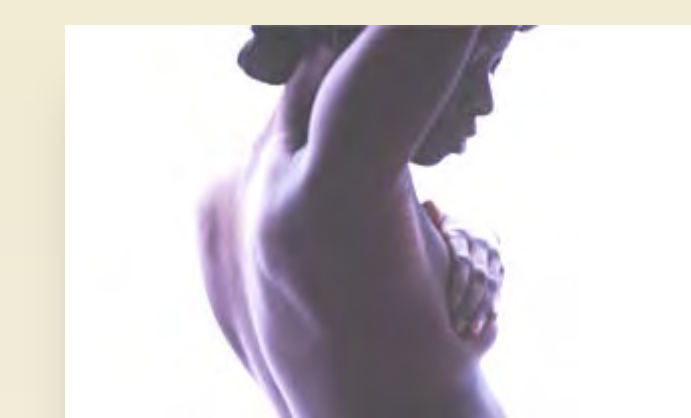
On the other hand, if we divide women into groups by age and/or life stage we may ignore important similarities among groups of women or we may assume that problems facing one group of women are not relevant for most or all women.

Issues that are shared across age and life stage include: financial stability, body image, intimacy as well as caregiving, work/life balance and social isolation.

*... in one fell swoop I was told that everything that was feminine to me was gone. I was losing my breast, I possibly couldn't have children – they were big things ... women are meant to have children. It's all right if you choose not to have them, but to be told you can't have them ... all of a sudden, my choices for my life ... everything I had planned were being taken away from me.*

## 6. Conclusion

*It was funny and tragic at the same time.... They were just a hilarious bunch of girls. One young girl who was in her 20s, she had lost her fertility; she was joking she got to go through menopause at the same time as her mother! I remember standing about one night and we were doing the top ten reasons for going through chemo! ... So no, I don't think I would have got through without them.*



As we work to understand the experiences and needs of women living with breast cancer, we need to:

- ❖ appreciate that words like “young” and “old” are laden with meaning that can create stigma;
- ❖ recognize that age and life stage are neither simple nor separate categories;
- ❖ ask women at **every age and life stage** what a diagnosis of breast cancer means to them and what they need;
- ❖ ensure that women at **every age and life stage** are involved in the design and delivery of services.

