

DEDICATED EXPERIENCED SUPPORT



sharecancersupport.org



A close-up, high-contrast portrait of an older woman's face. She has dark brown skin, deep wrinkles, and a gentle, contemplative expression. Her eyes are light-colored. She has curly, grey hair. The background is blurred, showing hints of blue and green.

AN UNHEARD MAJORITY:
How Older Women Experience
a Breast Cancer Diagnosis
EXECUTIVE SUMMARY

Dear Colleagues —

SHARE Cancer Support started as a lone support group for women with breast cancer. In 1976, Dr. Eugene Thiessen brought nine of his patients together, realizing they had no one but him to talk to about their diagnosis. This was our first support group.

From this compassionate origin, SHARE has grown into a comprehensive support system for women with breast, ovarian, uterine, cervical, and metastatic breast cancer. We have paid particular attention to diverse and underserved women with our programs in Spanish for monolingualistic patients, with outreach to the African American/Black communities, and with peer support in many languages.

Listening to patients every day, in our support groups and Helpline calls, we have a unique view of what concerns patients, and how they feel about their diagnosis, treatment, and care. Of course, many of our SHARE constituents are older women. The median age of diagnosis of breast cancer is 63, which means the majority of the women diagnosed with breast cancer each year are in their 60s, 70s, and 80s. And as we are living longer than ever before in the history of women, the number of older breast cancer patients will continue to grow.

Understanding this group of patients is paramount. That's why we surveyed a large sample of older women with breast cancer — 1,000 women nationwide and across four defined age groups — to create SHARE's first-ever report, *An Unheard Majority: How Older Women Experience a Breast Cancer Diagnosis*.

I want to thank Pfizer Oncology for their support of this project: This study would not have been possible without the help of Joanne C. Ryan, PhD, RN, Medical Director, Breast Cancer, US Medical Affairs, and Katrina Johnson, Director, Advocacy, and Professional Relations.

At SHARE, we believe in the power of women helping women, whether one on one, through educational events or support groups — or through important research such as this report.

We invite you to study and share our findings, and to connect with SHARE Cancer Support for more information about the work we do, and the women we serve.

Warm regards,



Carol Evans
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Executive Summary

Every day, some 900 Americans receive terrifying news from their doctor.

It's breast cancer.

Breast cancer strikes people of every age — and yet, you wouldn't know it from most consumer media coverage of breast cancer discoveries, treatments, and patients. For even though ***the average age of diagnosis is 63***, very little is known about the experiences and insights of women ages 70 and older, even as this population grows.

With this in mind, SHARE conducted a national, online survey of 1,000 women with breast cancer between February and April 2021. ***Our goal: to find out how older women experience a breast cancer diagnosis and how that experience differs from those of women diagnosed at a younger age.*** We wanted to know how decisions were made, where support was needed and given, and how older women view the patient-provider relationship versus that of young women, especially in terms of feelings of trust.

Most importantly, we wanted to uncover what impact, if any, age has on how women answered our questions. The results, some of which are surprising, are provided here and suggest specific and strategic ways healthcare providers can better serve patients.

In this report, we defined older women as those 60 years of age and older. We surveyed 250 women each in three defined age groups — 60 to 69 years, 70 to 79 years, and 80 years and older — and compared their responses to another group of 250 women, ages 59 and younger. (**For more information, see Appendix A: Survey Methodology and Demographics**)

In 2018, women ages 60 and older comprised more than 60 percent of all new breast cancer diagnoses.¹ Compared to young women, breast cancers in older women are thought to be more biologically indolent² and difficult to treat due to a higher rate of comorbid health conditions. Even in the older woman who is considered “healthy” for her age, the recognizable physical and mental health changes that naturally occur with aging make a diagnosis of breast cancer more problematic later in life.

This study builds upon the oft-cited report, *Ensuring Quality Cancer Care*,³ issued in 1999 by the National Academy of Medicine (NAM), formerly known as the Institute of Medicine. This report describes the ideal care cancer patients should receive. For breast cancer treatment specifically, the NAM details several quality problems, including “inadequate patient counseling regarding treatment options,” and the lack of adequate studies of reasons for failing to deliver high-quality care.



Our study attempts to answer that call by standing in the shoes of an older woman diagnosed with breast cancer to better understand what the NAM refers to as the patient's "knowledge, attitudes, and beliefs" regarding cancer treatment.

Older women with breast cancer represent a unique population of women that has gained experience with the healthcare system over time. Still, knowing how to find the information they need, the outside support they require, and how to play — or even, demand — a role in truly shared decision-making with their healthcare provider can still leave gaps that we highlight in this report.

It is within this context that our survey of older women with breast cancer can shed light on what is needed to optimize the diagnosis and treatment for the thousands of women who will follow in their footsteps each year.

Key Observations from the Survey

Older women with breast cancer, especially those 80 and older, believe their age had an impact on how they were treated as a person and how their healthcare team communicated with them.

- 1. As women age, they rely more on resources outside their medical team for information and support when diagnosed and undergoing breast cancer treatment.** Anticipating these needs upfront, regardless of whether they are mentioned by the woman, will lessen the likelihood she will second guess her treatment decisions later. When making treatment decisions, those younger than 70 years are much less likely to seek information from pharmaceutical companies, books, TV ads, and magazines, and are more likely to use medical/health websites, other professionals, and cancer organizations than women older than 70 years.
- 2. As women get older, their trust in their medical team decreases.** Although most women have high levels of trust in their medical team, our survey found that a startling one in four do not. Recommendations on how to improve trust in the medical team include providing printed materials to read after appointments, welcoming a family member or friend to the appointment, remaining in contact via follow-up calls, and utilizing the patient's native language whenever possible.

- 3.** *Women over 80 were less likely to think they experienced a shared decision-making process.* Introducing a collaborative decision-making process reassures patients that their wishes and preferences are valued by the healthcare team, and will be a key aspect of any treatment plan.
- 4.** *Healthcare providers should discuss the impact of breast cancer treatment holistically* with the broadest view of mental, social, emotional, financial, and sexual health, and lifestyle needs regardless of age or race.
- 5.** *Regardless of age or race, women diagnosed with breast cancer should be given the option to participate in a relevant clinical trial* so that treatment outcomes adequately address the unique needs of women like them. Women aged 70 to 79 years most frequently reported conversations with their healthcare team about the opportunity to participate in a clinical trial.
- 6.** *Financial concerns, especially out-of-pocket costs for Latinas and those on Medicaid, remain critical to patients* with breast cancer despite public and private health insurance coverage.
- 7.** *Older women (those ages 70 or older) were most likely to feel they did not have sufficient time to consider options before starting treatment.* A diagnosis of breast cancer can be overwhelming, and steps to minimize confusion and reinforce information are needed as a woman ages.

“Studies are needed to find out why specific segments of the population do not receive appropriate cancer care. These studies should measure provider and [patient] knowledge, attitudes and beliefs, as well as other potential barriers to access to care.”

— *Ensuring Quality Cancer Care,*
National Academy of Medicine