

DEDICATED EXPERIENCED SUPPORT

SHARE

sharecancersupport.org

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

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 monolingual 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
CEO and Executive Director
SHARE Cancer Support
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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

Demographics

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. In this report, we defined older women as those 60 years of age and older. **(For more information, see Appendix A: Survey Methodology and Demographics and Appendix B: Findings by Location of Residence.)**

Does Age Alone Really Impact Care? Yes.



Our survey of 1,000 women diagnosed with breast cancer showed that 38 to 66 percent of women felt that their age impacted their treatment and how they engaged with their healthcare providers.

In contrast, respondents younger than age 70 were more likely to say that they believe age influenced how their healthcare team treated them as a person or communicated with them as well as their treatment plan “a little” or “not at all.” Even among those aged 60 to 69, 45 percent felt that age influenced their treatment plan only “a little” or “not at all.”

Older women are undoubtedly facing retirement, comorbid health conditions, death of a parent or spouse, enrollment in Medicare, declining income, and/or enhanced reliance on external support to maintain their health and well-being. Many of these life changes are abrupt, making the added diagnosis of breast cancer a challenging and complex juggling act. Healthcare providers, cancer support groups, and others who specialize in cancer care are encouraged to recognize the sensitivities of older women and approach them with the added care and concern they need.

Older women have unique concerns about breast cancer treatment and understand their own bodies, what they need to receive care, and the physical and mental health they wish to maintain in their elder years. The needs of older women are different than younger women, as illustrated in this report and in the aging population at large.

This survey did not explore how age impacts treatment and care. But knowing that it does behooves healthcare providers and cancer support groups to address an older woman’s concerns in a transparent and open manner upfront. A shared decision-making approach to counseling offers the most beneficial approach to accomplish this, as it accommodates the individual patient’s wishes and concerns in a manner that is sensitive to her preferences.

“Well, at your age, if it is cancer, you wouldn’t do anything, would you? I think that’s my decision, not my insurance company’s. [They were] acting like I was too old to bother with it.”

— Ginny, diagnosed at age 41 and 67

Just as it is often said in medicine that “children are not small adults” so too must we remind providers that older patients are “not simply adults who have lived longer.”

Five Factors Influencing Treatment Decisions for Older Women

To better understand aspects of care most important to older women with breast cancer, the *Older Adults* survey asked women to report on those factors most influential to their treatment decisions at the time of diagnosis.

Respondents answered the survey approximately 5 years after their diagnosis, and could therefore reflect on their treatment decisions, and the factors that influence these decisions the most, including those beyond their physical health.

Five key considerations stood out from our survey:

1. Time to Consider Treatment Options

Overall, most (83 percent) respondents said they felt “very informed” or “somewhat informed” regarding their treatment options. ***The survey’s oldest respondents, ages 80 and above, were more likely to feel “not informed enough” or “not informed”*** (28 percent) compared to 11 percent of women 59 years old and younger.

Although most (73 percent) respondents of all ages felt they had enough time to consider their options before starting treatment, one in five respondents (22 percent) felt they did *not* have enough time.

While these responses are a positive reflection of the patient/provider relationship, one in five respondents would have preferred more time to consider treatment options.

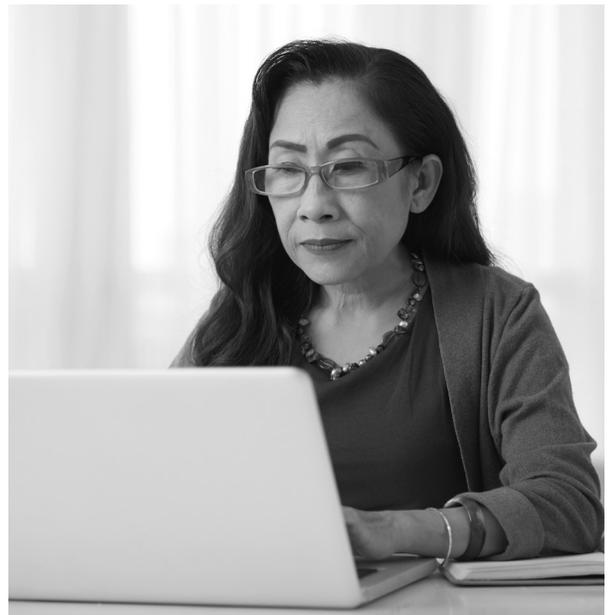
2. Emotional and Mental Well-being

Our survey unsurprisingly found that healthcare providers and their patients discussed a wide range of topics before and during treatment — however, the **topics discussed varied across age groups**. For example, respondents ages 70 and older were more likely to recall conversations about mental and emotional topics — with “feelings of depression” and “mood” among their top five recollections. In contrast, those younger than 70 remembered practical topics such as “ability to care for yourself” and “nutrition” among their top five recollections.

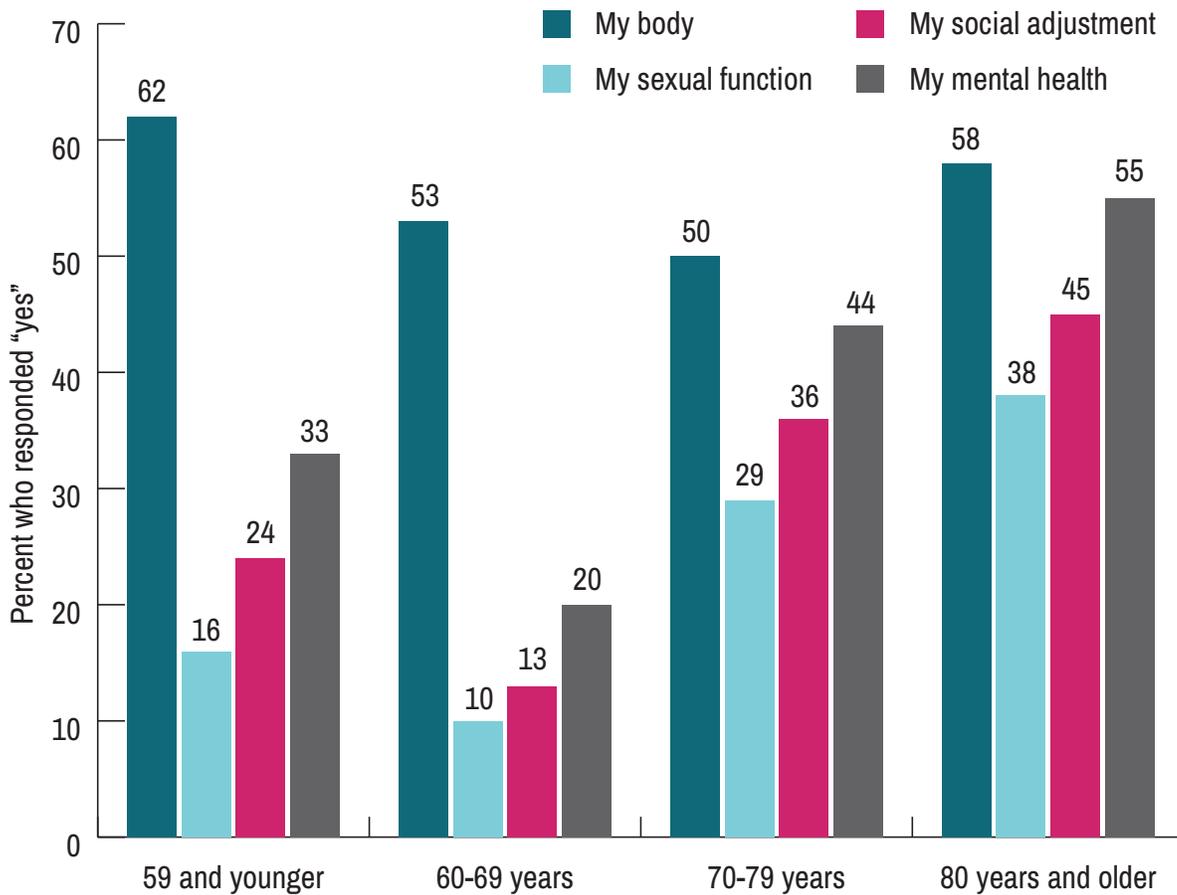
“When you see a doctor, that doctor is practically breathless from seeing a patient before you and then running off to see another patient after you. This is not a person that you are going to have a conversation with about your anxiety or depression. [The system] is not set up to absorb or entertain or gently handle that kind of issue.”

— Karen, diagnosed at age 68

When healthcare providers discussed the potential impact of surgical treatments beyond the physical impact on the woman’s body, mental health was the main topic of discussion in more than half (55 percent) of respondents ages 80 and older, but this topic was discussed with less than half (20-33 percent) of women younger than age 70. **Women over the age of 70 were much more likely to report that their healthcare providers discussed the potential impact of surgical treatment on sexual function and social adjustments**, with women over age 80 reporting these discussions more frequently than those of any other age group.



My healthcare provider and I discussed potential impacts of surgery on:



[When referring to her own experience at the doctor's office...] "You are too old to be thinking about breast implants."

—Shirley, diagnosed at age 64

“Radiation was terrible. It wasn’t the effect on my breast tissue...but the position you had to maintain for breast cancer treatment was terrible. With your arms above your stomach. It was awful, and I was in terrible neck and back pain. I got so upset with the whole thing.

My oncologist spends 10 minutes looking at her computer and the results from all my tests and then 3 minutes palpating my chest. It’s a very short visit, and she spends more time looking at the computer than at me. The healthcare system is just very burdened these days.”

—Nancy, diagnosed at age 76

“I wasn’t given options. I had a mastectomy. I was curious about reconstruction, but I was poo-pooed like you are so old; what are you thinking about that for? I was very much aware that my age cut off a lot of options for me.”

—Carolee, diagnosed at age 79

Two-thirds of respondents (68 percent) reported having been provided resources about where to seek emotional support during treatment, with those ages 80 or older most likely to report having been offered such resources (78 percent). However, although respondents across all age groups, race/ethnicity, and payer type (e.g., Medicare, private insurance) cite some level of concern about their mental and emotional health, one in five do not recall being provided any resources to seek emotional support during treatment. This gap must be addressed by healthcare providers, cancer support groups, and patient advocacy organizations as a critical, if not fundamental, component of comprehensive care for all women during breast cancer.

“I just felt like I was on a cancer conveyor belt. I just did what they told me, which is very unlike me. Nobody asked me much about feelings or emotions.”

—Carolee, diagnosed at age 79

3. Patients’ Allies

Finding Support When Making Treatment Decisions

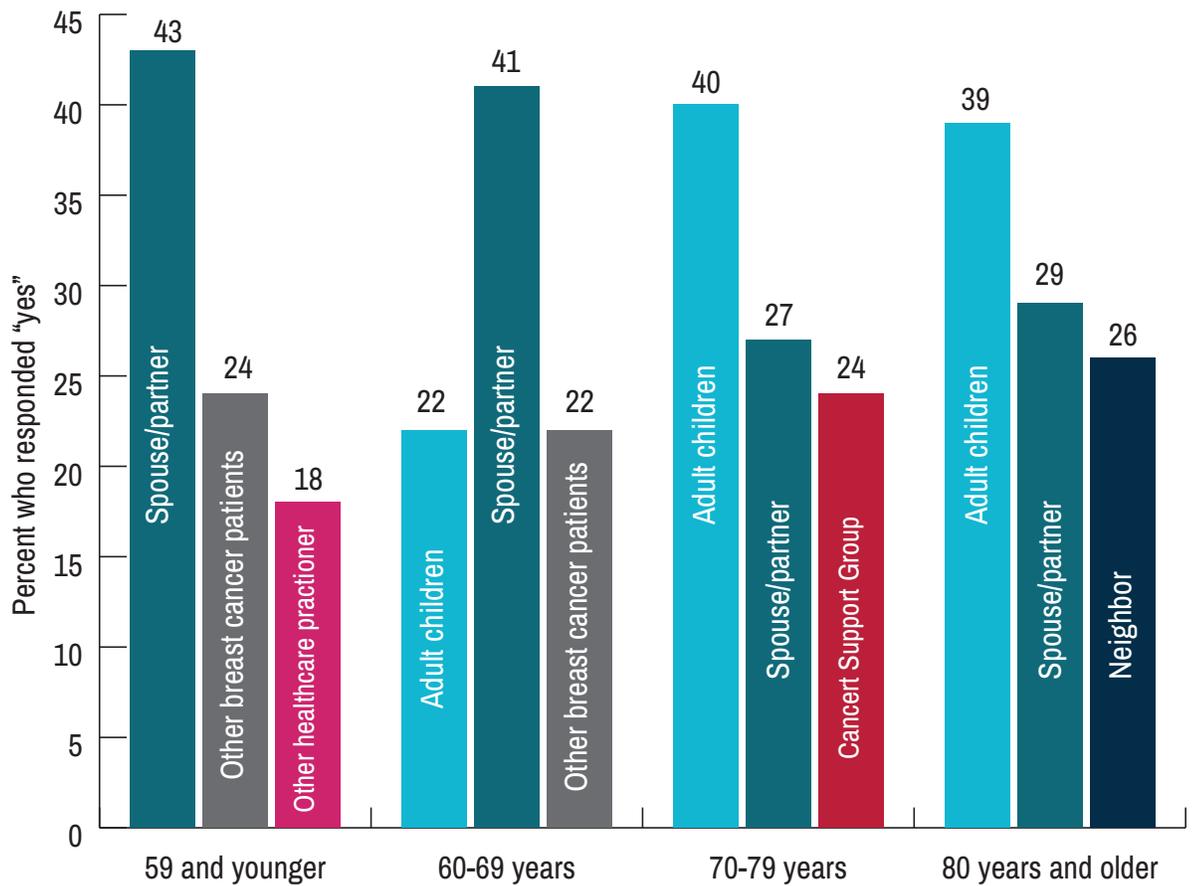


When it comes to advice about treatment decisions, our survey found clear differences among age groups about who was included in their support circle. Respondents younger than 70 turned to their partner/spouse approximately 40 percent of the time, whereas those 70 years old or older turned to their adult children. This may be due to a greater number of widows among the oldest respondents who rely heavily upon adult children as they age.

Our survey clearly showed that age 70 is a rough dividing line for how others provide support with decision-making. For example, respondents 70 and older included neighbors as part of their personal support team (20-26 percent of the time) versus only 2 percent among those younger than 70. Similarly, nearly a quarter of women over the age of 70 reported seeking help from a cancer support helpline, whereas those younger used this source only 7 percent of the time.

The importance of connection with other breast cancer patients was seen across our defined age groups (21-24 percent). Peer-to-peer patient support helps patients understand the day-to-day impact of treatment decisions beyond what is presented by the medical team. Indeed, patient advocacy organizations have extensive patient support groups, educational resources, and mentoring programs to pair recently diagnosed patients with those who have faced similar treatments.

Sources of support when making treatment decisions: top 3 selected by each age group



Older women could likely benefit from cancer support groups that involve discussions and decisions they are now facing. They can offer the comforting presence and practical support women in breast cancer treatment need, especially when others don't know what to say or how to start a conversation with someone who has cancer.

Finding Support During Treatment

Our survey found that older women turned to a variety of sources for support during breast cancer treatment for activities of daily living such as meal preparation, transportation, yard work, and home maintenance. For women ages 79 and younger, family (44-61 percent) and friends (39-51 percent) ranked highest as a source of support. However, women ages 80 and above reported a more even distribution and range of responses.

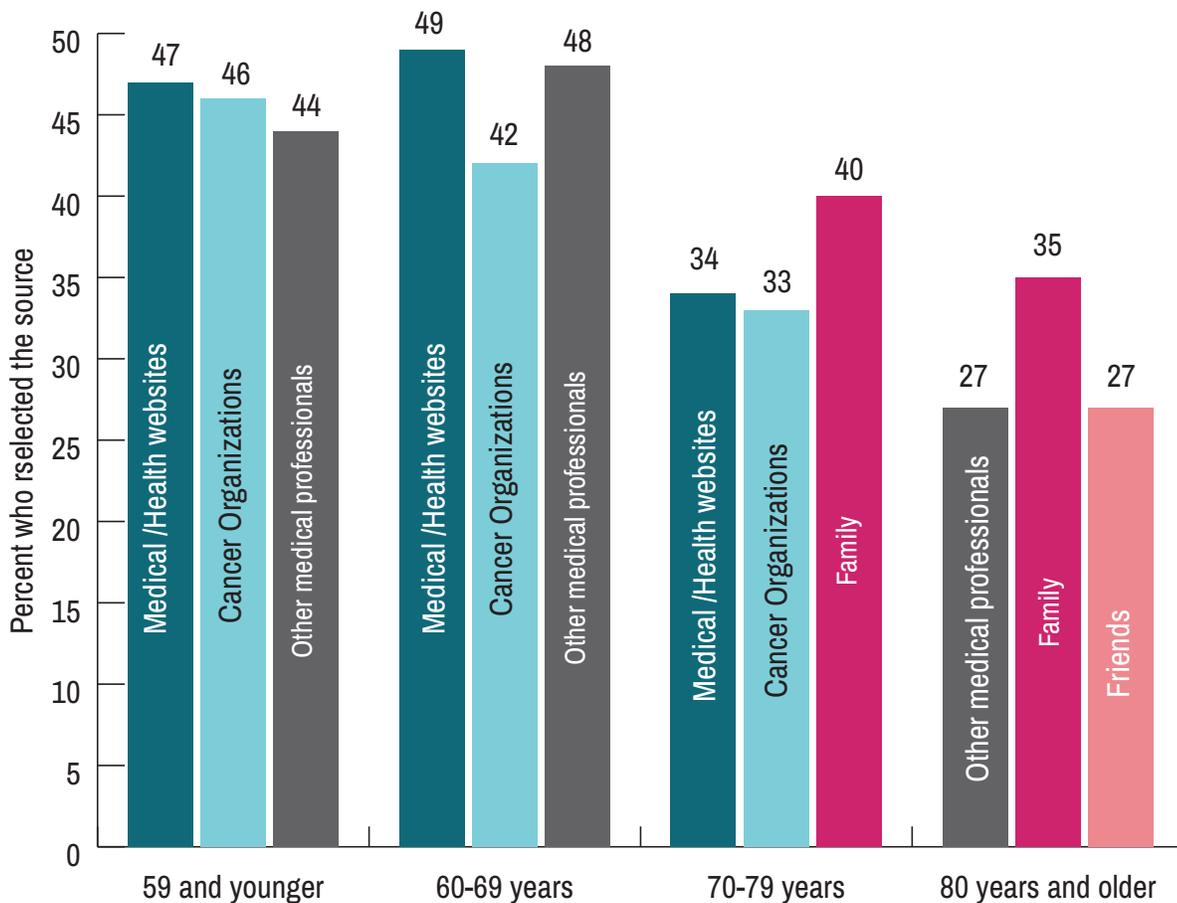


About one-fourth of all respondents turned to a cancer support group for support during treatment. These organizations provide vital education for older women and can direct them to a wide range of services based upon their needs. Cancer support organizations like SHARE have the advantage of focusing on care specific to the patient and resources for referrals beyond the assistance they provide.

4. Additional Resources for Treatment Decisions

Respondents younger than age 70 cited medical and health websites, cancer organizations, and other medical professionals as their go-to resources for making treatment decisions. In contrast, those ages 70 to 79 were most likely to reach out to family (40 percent) and to utilize other resources.

Sources of additional information regarding treatment options: top 3 selected by each group



Interestingly, differences in utilizing outside resources were most notable in respondents depending upon their source of insurance: Those on Medicaid most often sought information from their family (52 percent), whereas women with employer-based insurance more often turned to medical/health websites and cancer organizations versus resources such as books, TV ads, magazines, and nonprofit organizations.

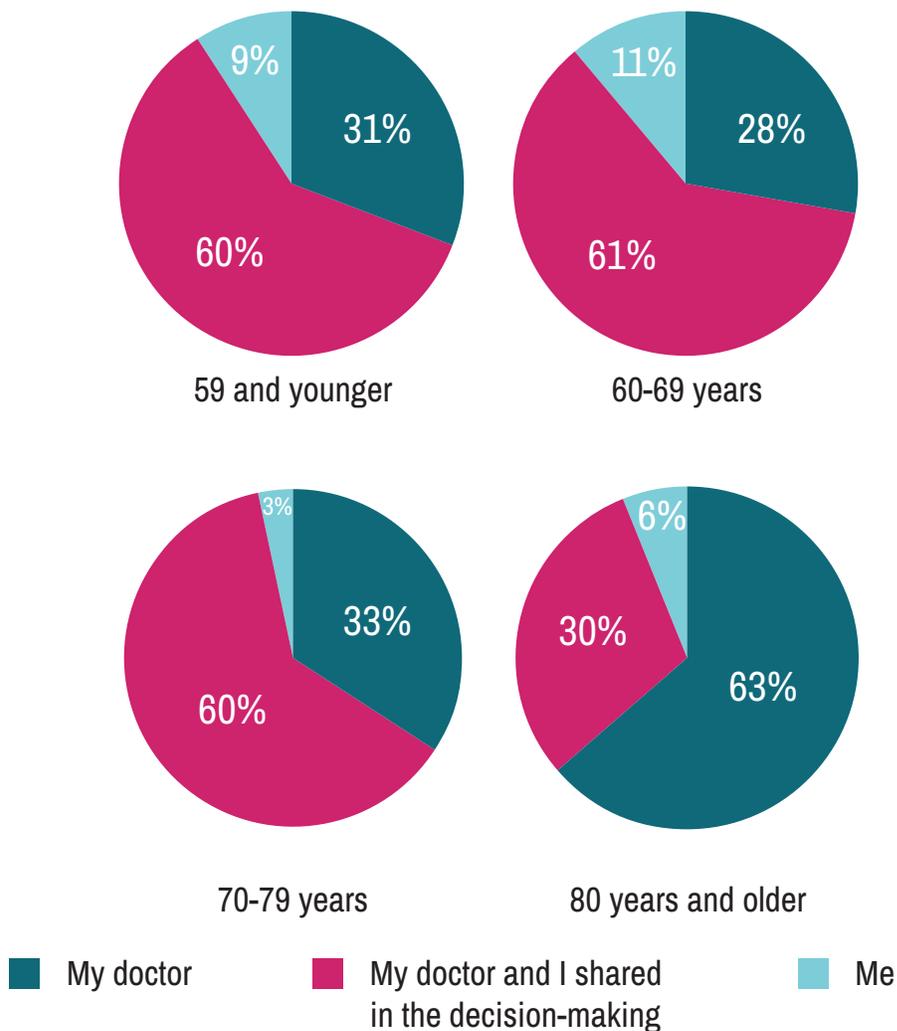
For several decades, pharmaceutical companies have played a role in educating patients with direct-to-consumer advertising, making it the most prominent type of health communication encountered by the public.⁴ Respondents to our survey reported relying upon pharmaceutical

companies to a varying degree based on their insurance type and age. Those with employer-based insurance (8 percent), Medicaid (13 percent), and Medicare (17 percent) reported relying on information from pharmaceutical companies, whereas no respondents with Affordable Care Act plans did. Moreover, respondents younger than age 70 were less likely to say they sought information from pharmaceutical companies, whereas those aged 70 and older did so frequently (22-24 percent).

5. Shared Decision-Making

Our survey found that **women are making fewer of their treatment decisions as they get older**. Nearly two-thirds (63 percent) of **respondents ages 80 and older reported that their doctor made most of their treatment decisions**. Notably, this was nearly twice the rate of this response of any other age group. Although this may reflect the “doctor knows best” approach that dominated healthcare decision-making until recent years, the other age groups were more likely to report the preferred approach of shared decision-making with their doctor.

Most of my treatment decisions were made by:



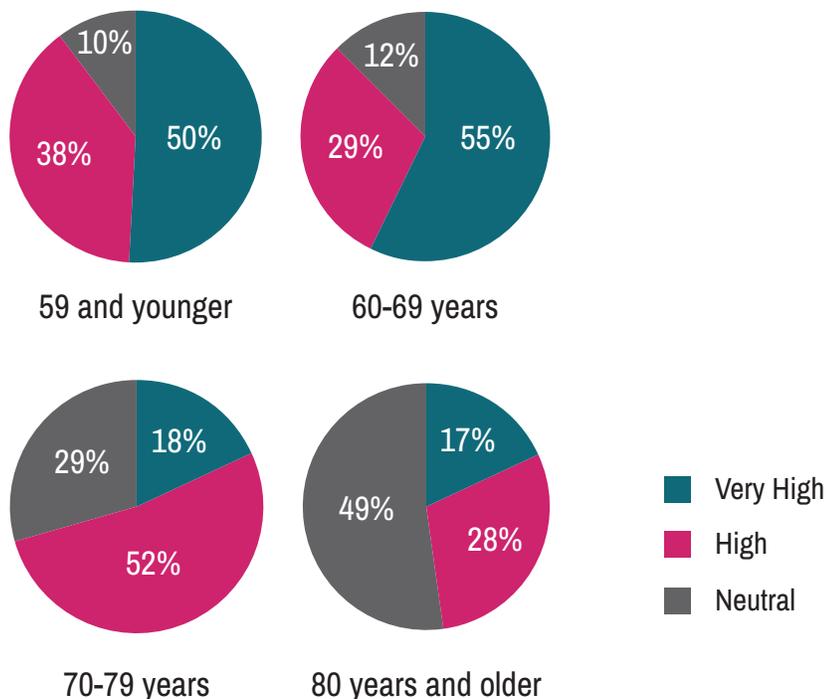
Shared decision-making is a structured way to incorporate evidence, patient values, and preferences into medical treatment choices. This process can support conversations leading to better-informed decisions that align with what matters most to patients.^{5,6} Advantages of this approach include higher patient compliance with treatment, greater confidence in the process, less anxiety, better communication between the patient and physician, better outcomes, and less uncertainty.^{7,8,9}

Hispanic survey respondents were more likely than other racial and ethnic groups to report that their physician made most treatment decisions (55 percent). Not surprisingly, Hispanic women were also the least likely to report an experience of shared decision-making during breast cancer treatment. Further study is needed to understand the factors important to older Hispanic women with breast cancer that would foster a shared decision-making approach.

The Role of Trust in Treatment

Among all respondents, a startling one in four felt “neutral” or “low trust” in their medical team. The oldest women we surveyed (ages 80 and above) reported the lowest levels of trust with their medical team, with 55 percent reporting a “neutral” or “low level” of trust. By comparison, approximately half of women age 79 and younger reported “very high” or “high” levels of trust in their medical team during treatment. As women get older, their trust in their medical team decreases.

Level of trust with my healthcare provider



Women who reported “neutral” or “low trust” suggested four ways to improve trust of healthcare professionals:

1. Leave with printed materials to read later (32 percent).
2. Call or check in with my doctor and other healthcare team members (32 percent).
3. Know what questions to ask (31 percent).
4. Connect with a cancer support group (30 percent).

Clearly, there is not a “one size fits all” approach to improving trust between the older woman with breast cancer and her medical team. The simplest of actions — offering printed materials to take home and providing connections with a cancer support group — can have a significant impact on a newly diagnosed patient who is starting a long, and potentially frightening, journey for the first time.

Respondents ages 80 and above also placed high priority on including a family member/friend at their medical appointments, researching more information on their own, and working with medical professionals who speak their native language. These suggestions can be reasonably implemented by medical teams and organizations involved in patient education and cancer support.

“My doctor called me at work to let me know about my cancer diagnosis even though she had my home number and the number of my emergency contact. I was really, really upset about this.”

Shirley got a second opinion.

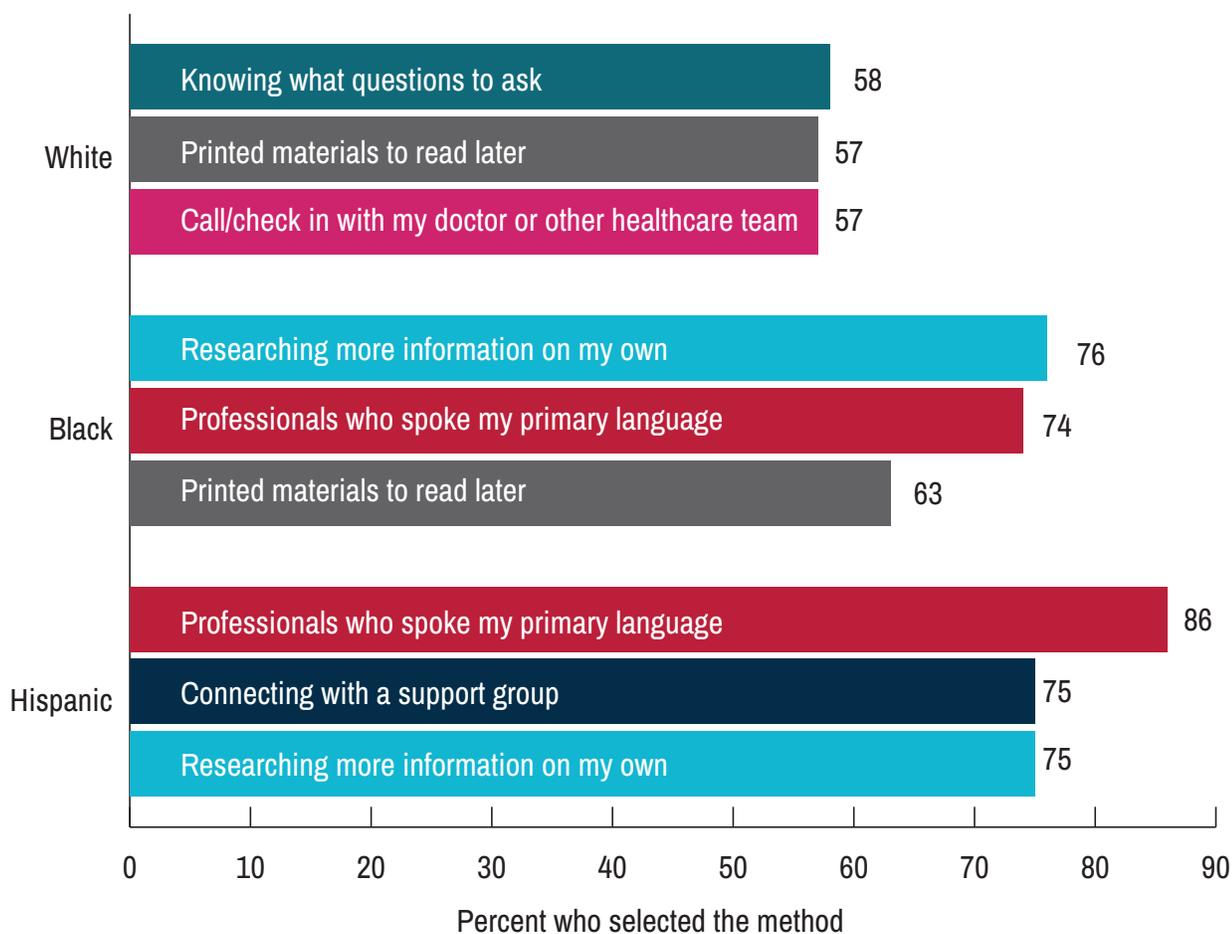
“This doctor was very different than the first doctor. The second doctor said, ‘Don’t worry, we will get through this.’ She came and lay beside me while I was getting the medication. Then I felt I’m home. I’m home. It was a warm and fuzzy experience. Prior to that, I was very scared and very anxious. I have no relatives at all in the US. I live by myself. No children. Never married. For once, I felt there is someone who really cares.”

—Shirley, diagnosed at age 64

Racial/Ethnic Differences in Building Trust

Recommendations for how to improve trust also vary by race and ethnicity, further reflecting the myriad of ways in which individuals perceive others to be trustworthy in the healthcare setting.

**Ways my medical team can increase trust (age 70 years and older):
top 3 selected by each group**



Most women (87 percent) felt comfortable calling their healthcare team; however, about one in ten did not.

“I always feel very guilty talking to anyone [at the doctor’s office], and they don’t want to talk to me either.”

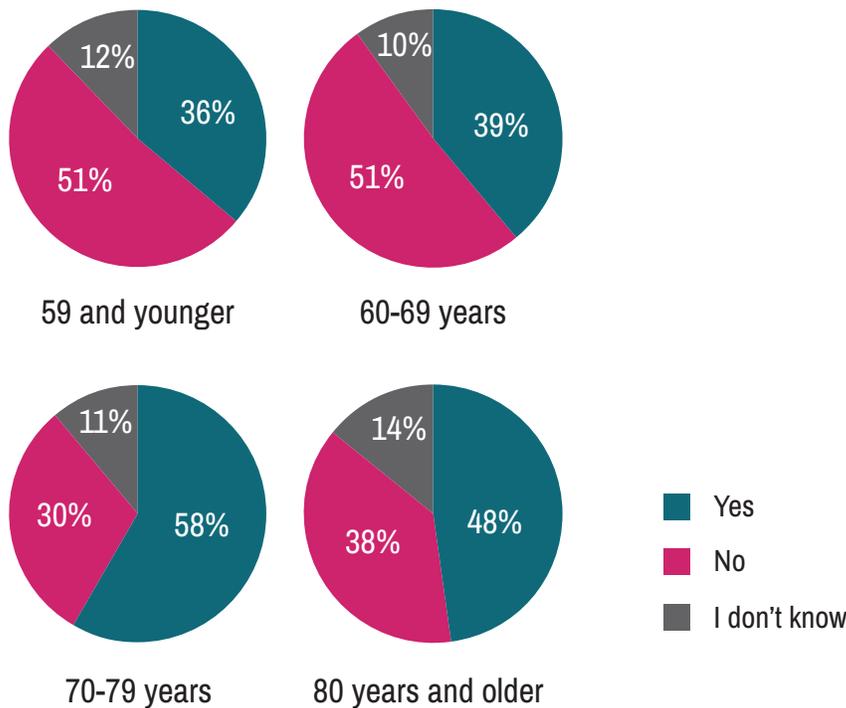
—Diane, age at diagnosis unknown

Interactions with the medical team during treatment are essential for women of all ages. Our survey also found differences in interactions among certain racial/ethnic groups. For instance, 15 percent of Black respondents did not feel comfortable calling their healthcare team and were more inclined to rely on learning more on their own time (through printed materials to read later, more time to research on their own). Of note, only about 5 percent of all active doctors are Black or African American, according to the Association of American Medical Colleges,¹⁰ making it incredibly difficult for Black women to find care that reflects their own life experience.

Looking Back, Considering Anew

Perhaps one of the most striking findings of the survey was that nearly half (45 percent) of all respondents claim that they would have made different decisions regarding their treatment knowing what they now know as a breast cancer survivor, with women over age 70 more likely to agree.

Looking back, would I have made different decisions regarding treatment knowing what I now know as a breast cancer patient?



While being “uncertain” about a treatment decision in the past is not the same as “decision regret,” the level of second-guessing is higher in this survey than has been reported for decision regret among breast cancer patients overall.¹¹

Additionally, about one in ten (12 percent) responded “I don’t know” when asked about whether they would have made a different decision based on what they now know. This level of uncertainty was highest among those aged 70 to 79 (58 percent), and those who identify as Hispanic (63 percent).

When thinking about why so many respondents might have made different decisions regarding their breast cancer treatment, it is important to note that the youngest respondents (ages 59 or younger) completed the *Older Adults* survey on average 10 years after diagnosis, whereas older women aged 60 and older completed the survey within an average of 3 years after diagnosis. Our survey does not have sufficient data to draw conclusions as to whether the time between diagnosis and survey completion had an impact on responses. However, women surveyed at only 3 years out from diagnosis may still have been battling the impact of treatment on their health and well-being or their experience may be fresher in their memory. Respondents aged 60 and older may have been more likely to question their treatment decisions than younger women who responded further out from treatment.

Care for Others During Treatment

For many older women, their breast cancer treatment course and preferences for seeking support may be influenced by the additional responsibility of being a caregiver to someone else during their own treatment. High numbers of women who were Latina (44 percent), Black (59 percent), and over age 80 were caregivers to someone else. Additional support and community resources would be helpful to these women to balance their own care and needs while tending to someone else.

Prevention and Screening Practices

While nearly half (49 percent) of all respondents reported having had a mammogram in the prior year, our survey still found clear signs of discouragement against such screenings due to age, with women of color reporting discouragement more frequently than white women.

54 percent of Latinas and 43 percent of Black respondents reported being discouraged from having a screening mammogram, and nearly half of all respondents on Medicaid said they were discouraged from requesting a screening mammogram “because of age.” By comparison, white respondents and those younger than age 70 were among those least discouraged from having a screening mammogram due to age.

All told, 56 percent of respondents ages 80 and older had not had a screening mammogram in the 1 to 3 years prior to completing this survey. **(For more information, please see Appendix C: SHARE Recommendations on Screening Mammograms.)**

Respondents were also asked if they had been tested for mutations or changes in BRCA1, BRCA2, or other genes. Most respondents, regardless of age, said they have been tested, including more than 60 percent of those older than 80.

Financial Concerns and Insurance Status

When it comes to breast cancer treatment, financial counseling is an integral part of comprehensive care. About 40 percent of all respondents received some type of financial counseling, with Hispanic women reporting the highest rates (77 percent).

Excluding those who did not have surgery, Latinas were most likely to say that out-of-pocket costs are important in their decision-making regarding treatment. By comparison, such concerns were considerably less important among white respondents.

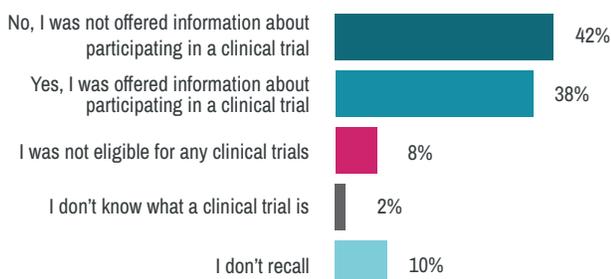
Compared to respondents with sources of payment such as employer-sponsored insurance, Medicaid respondents were more likely to be a caretaker to someone else during their own treatment, were more likely to have financial counseling, had considerably fewer family members to support them during treatment, and were the most concerned about out-of-pocket costs.

Older Women and Clinical Trials

Overall, few people participate in trials, and those who do participate do not always represent the U.S. population. According to the Food and Drug Administration, participation is especially low for certain populations, including adults ages 75 or older, as well as those from certain racial and ethnic groups.¹² Such underrepresentation makes it harder for clinicians to predict how patients from these underrepresented groups will benefit or tolerate particular therapies.¹³

Clinical Trial

Over half of women were **not offered or could not recall being offered** information about participating in a clinical trial.



Respondents were asked if they were offered information about participating in a clinical trial for their breast cancer treatment.

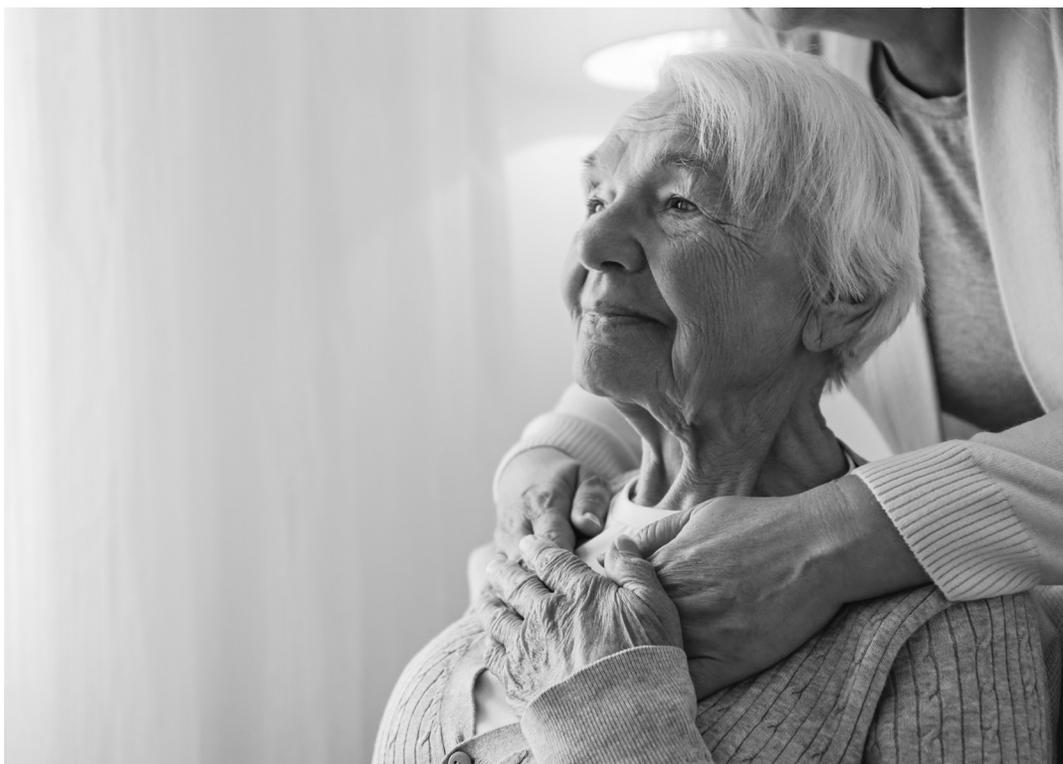
In our study, however, women ages 70 to 79 (48 percent), women on Medicaid (48 percent), and Latinas (56 percent) were those most often offered information about participating in a clinical trial. This is possibly due to a growing effort to increase the diversity in clinical trials to reflect the population more accurately. With so many new and promising cancer treatments being developed, the need for clinical trials to test older women efficiently and effectively has never been greater.

Unfortunately, healthcare providers may not discuss participation in a trial for many reasons. For example, an older patient may have comorbidities that make tolerating aggressive therapy difficult, or an older patient may not have adequate family support. The National Cancer Institute of the National Institutes of Health encourages healthcare providers to present the option to participate in clinical trials to their patients so that they can make informed decisions about trial participation together.¹⁴

Endnotes

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Appendix A: Survey Methodology and Demographics

SHARE Cancer Support commissioned Qualtrics to perform an online quantitative survey in April 2021 to determine the characteristics and needs most important to older women with breast cancer. Responses were obtained from 1,000 women who were over the age of 18 and who had been diagnosed with breast cancer. Segments explored were age at diagnosis, race/ethnicity, insurance, location of residence, and region.

We surveyed 1,000 women with breast cancer. Sample quotas were set for each age group:

- Ages 80 plus: 242
- Ages 70 to 79: 245
- Ages 60 to 69: 262
- Ages 59 and younger (control group): 251



To address overlap between Hispanic origin and racial categories, respondents who said they were of Hispanic origin were not counted in the Black and white categories so that the racial sub-groups do not include respondents of Hispanic origin.

Although the survey collected responses from women of Asian, American Indian/Native Alaskan, and Native Hawaiian/Pacific Islander descent, these sub-groups had insufficient sample size for reporting

purposes. Combined, these groups account for 10 percent of those surveyed.

In an effort to generate responses from its database of 4,000-plus volunteers, support group members, and event attendees, SHARE offered an incentive of a \$10 gift card upon completion of the survey.

The survey was only conducted in English, with 1 percent noting their primary language was Spanish.

Survey Notes

The average age of the control group (age 59 and younger) was 46 at diagnosis, and 57 at the time of the survey. The average age of respondents ages 60 years and older was 74 at diagnosis and 77 at the time of the survey. As such, respondents in the control group (59 years and younger) were on average, 30 years younger than those in the 60 years and older group when diagnosed. Some, but not all, differences in the survey findings can be attributed to this age difference at the time of diagnosis. Similarly, older respondents (60 years and older) completed the survey on average 3 years after diagnosis compared to an average of 10 years after diagnosis for the control group.

This report mainly focuses on the most illustrative and informative findings, which included differences according to age and race/ethnicity. Insurance type, location, and region of the country were less informative.

Demographics

Average age of respondent: 72 years

Average age when diagnosed with breast cancer: 67 years

Married or in a Domestic Partnership: 68 percent

Employment Status

Retired: 67 percent

Working: 19 percent

Not Employed: 14 percent

Highest Level of Education

Post-graduate degree: 15 percent

Some Post-Graduate: 3 percent

Bachelor's Degree: 20 percent

Associate's Degree: 20 percent

Some college: 23 percent

Technical/Vocational: 6 percent

High school: 13 percent

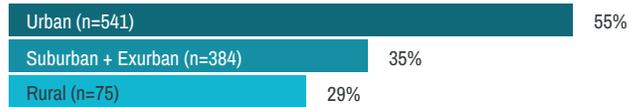
Some high school: 1 percent

Appendix B: Findings by Location of Residence

Findings by Location of Residence

Satisfaction in Treatment Decision

More than half of urban women would have made different decisions regarding treatment knowing what they know now.

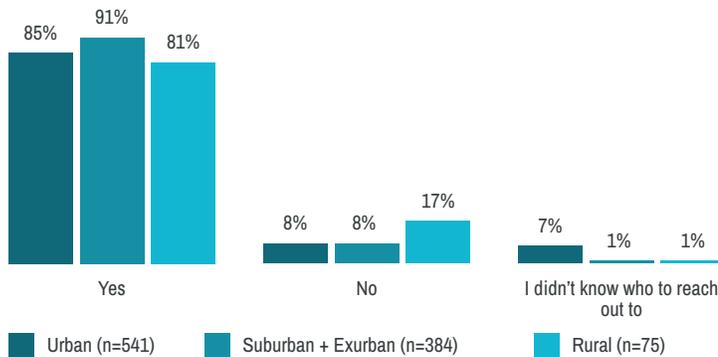


Respondents were asked if they would have made different decisions regarding treatment knowing what they know now.

Women who lived in rural areas were most likely to be satisfied with their treatment decisions compared to women who lived in other areas, but there are opportunities to improve patient experience for women in all locations.

Comfort Level

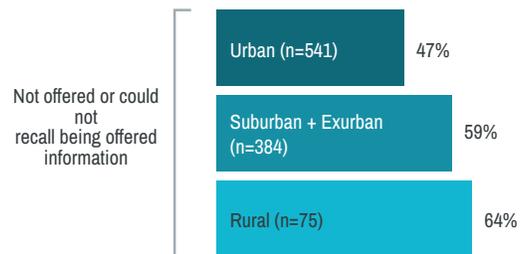
Over 15% of women who lived in a rural location **did not feel comfortable** calling their healthcare team and 7% of women who lived in an urban location **did not know who to reach out to** in order to contact their healthcare team.



Respondents were asked if they felt comfortable calling their healthcare team during treatment.

Clinical Trial

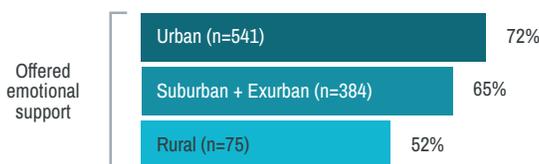
Nearly 2/3 of women who lived in a rural or suburban/exurban location **were not offered or could not recall being offered** information about participating in a clinical trial.



Respondents were asked if they were offered information about participating in a clinical trial for their breast cancer treatment.

Emotional Support

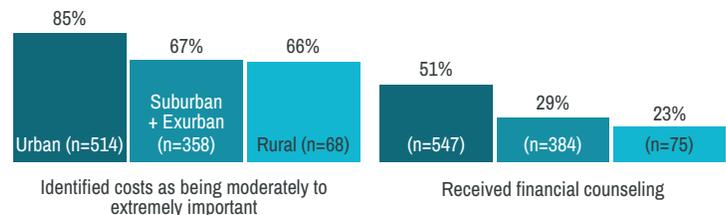
Women who lived in a rural or suburban/exurban location were less likely to be **offered emotional support resources**.



Respondents were asked if they were provided any resources about where to seek emotional support during treatment.

Financial Considerations

There was a disconnect between the number of women who identified costs as being moderately to extremely important and those who could recall **receiving financial counseling**.



Respondents were asked how important out-of-pocket costs were in their decision to proceed with cancer treatment. Separately, they were asked if they received any financial counseling related to their breast cancer treatment.

Appendix C: SHARE Recommendations on Screening Mammograms

Although screening guidelines vary, SHARE recommends that women over age 50 should come to a shared decision with their healthcare provider about frequency of mammograms and clinical breast exams based on risk of developing breast cancer, age, overall health, and expected life span. In general, women ages 50 to 54 are recommended to receive an annual screening mammogram, whereas women ages 55 to 74 are recommended to receive a mammogram once every 2 years. Women ages 75 and above should receive a mammogram once every 2 years if they are in good general health and have an expected lifespan of 10 years or more.



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**About SHARE**

SHARE is a national nonprofit that supports, educates, and empowers anyone who has been diagnosed with women's cancers, and provides outreach to the general public about signs and symptoms. We are a compassionate community of knowledgeable survivors, women living with cancer, and healthcare professionals. All of SHARE's services are free, and we are dedicated to serving women of all races, cultures, backgrounds, and identities. Because no one should have to face cancer alone.

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