Long-term survivors speak: patient perspectives on progress

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Disclosures

• Annie Ellis
  • None
Unlabeled/Investigational Uses

I will not be discussing any unlabeled or investigational uses of any pharmaceutical products or medical devices.
Objective

What are the perspectives of long-term ovarian cancer survivors (LTS) regarding progress?
Methods

Virtual Roundtable

• LTS were invited through social media survivor groups
• **14 LTS** attended 90-minute virtual roundtable moderated by two LTS research advocates
• Consent was obtained verbally for the roundtable, including consent for use of zoom picture
• Notes were taken during the session and common themes were identified

On-line Survey

• Distributed to roundtable participants to collect written consent, demographics and survivorship information
• Provided an opportunity to reiterate, clarify and expand on comments made during the session in a non-identified manner and to rank research needs
• Survey was shared with additional LTS who were unable to attend the virtual roundtable who wanted their perspectives to be included
• **23 surveys** were analyzed
### DEMOGRAPHICS (n=23)

<table>
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<tr>
<th>Age ranges</th>
<th>Age at diagnosis ranges</th>
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<td>50-59</td>
<td>40-49</td>
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<tr>
<td>60-69</td>
<td>50-59</td>
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<tr>
<td>70-79</td>
<td>&gt;70</td>
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<td>80-89</td>
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<table>
<thead>
<tr>
<th>Length of survival ranges</th>
<th>Cancer stage</th>
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<tr>
<td>5-9 years</td>
<td>Stage I</td>
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<tr>
<td>10-14 years</td>
<td>Stage II</td>
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<tr>
<td>15-19 years</td>
<td>Stage III</td>
</tr>
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<td>20-24 years</td>
<td>Stage IV</td>
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<tr>
<td>25+ years</td>
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<table>
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<th>Race</th>
<th>Hereditary mutation status</th>
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<tbody>
<tr>
<td>Asian or Asian American</td>
<td>Negative/no mutation identified</td>
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<tr>
<td>Black or African American</td>
<td>Positive for hereditary mutation</td>
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<td>White or Caucasian</td>
<td>Indeterminant/VUS</td>
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<td>Genetic testing not offered</td>
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<table>
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<th>Recurrent disease</th>
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<tr>
<td>Not Hispanic or Latino</td>
<td>No</td>
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</table>
Long-term Survivors Speak

Surgery has improved to consider optimally debulked

Addition of Avastin (bevacizumab) and PARP inhibitors as maintenance treatment

Survivorship planning and better information online

Prophylactic removal of Fallopian tubes and/or ovaries

No early detection test

mortality rate

Genetic testing to guide treatment choices

Structural barriers that continue to contribute to disparities in outcomes for Black women

Recognition of more rare types and how they develop

Palliative care has improved

Though available women still not being offered genetic testing or guidelines being followed

Not enough research and clinical trials

Slow development of tumor algorithms to determine who does better on certain treatments

Recognition of more rare types and how they develop

Though available women still not being offered genetic testing or guidelines being followed
Progress Themes

- Longer Survival
- Surgery
- Understanding Ovarian Cancer
- Hereditary Genetics
- Treatment
- Monitoring
- Quality of Life
- Survivorship
- 2007 Consensus Symptoms
Progress Details

**Surgery**
- Gynecologic oncologist
- Optimal debulking
- Zero residual
- Primary and neoadjuvant
- Robotic surgery
- Fertility discussions
- Egg storage

**Understanding Ovarian Cancer**
- TCGA:
  - Complexity, genomic chaos, CNV
  - Pathways
  - Somatic testing guidelines
  - Site of origin:
    - Fallopian tubes
    - Endometriosis

**Hereditary genetics**
- Discovery of hereditary mutations (BRCA1/2; Lynch; expanded panel)
- Discontinuation of gene patent
- Genetic testing / Cascade testing
- Guideline recommendations
- Opportunity for risk reduction:
  - Prophylactic surgery
  - Birth control pills
  - Embryo selection
Progress Details

**Treatment**
- Targeted therapies
- Maintenance
- PARP Inhibitors
- Bevacizumab
- Immunotherapy (some responses)
- Innovative clinical trials
- Shared decision-making

**Monitoring**
- CA-125
- Imaging:
  - CT
  - PET
  - MR
  - ultrasound
- Telehealth

**Quality of Life**
- Antiemetics
- Palliative/Supportive care
- Exercise
- Nutrition
- Increased acceptance of integrative/complimentary therapies

**Survivorship**
- Survivorship plans
- Better information online
- Access to support groups
Unmet Needs Themes

- Mortality Unchanged
- Lack of Early Detection and Screening
- Resistance
- Underutilization of Advances
- Disparities
- Limited treatment options
- Long-term Side Effects
- Cost
- Awareness
Unmet Needs Details

Underutilization of Advances
- Genetic testing
- Cascade testing
- Somatic testing
- Survivorship plans

Disparities
- Underserved & Marginalized:
  - Minorities
  - Rural areas
  - Socioeconomic
  - Underinsured
- Variations: practice and skill

Limited treatment options
- Non-BRCA
- Non-HRD
- Rare subtypes
- Resistant disease: primary and acquired

Long-term Side Effects
- NEUROPATHY
- Lymphedema
- Cardiotoxicity
- Tinnitus
- Secondary cancers

Awareness
- Optics: Older disease, Younger women overlooked for dx
- Lack of awareness: General public, General medical community

Additional research areas
- Endometriosis and ovarian cancer (clear cell, endometrioid)
- Strong family history with negative genetic testing
Survey: Which area of ovarian cancer is most important and should receive the highest priority?
Had difficulty ranking what was most important. Many of them were very important to me and I kept changing my mind.

Better treatment for all ovarian cancer types!

There should be a more accurate test than the CA125.

All areas are important!!! We need everything!
What has been helpful through treatment and survivorship?

- Survivor Community
- Support of Family & Friends
- Medical Team
- Insurance
- Self-Advocacy/Research
What has been helpful through treatment and survivorship?

"Access to other survivors, though I wish I also had had better access to juried journals for free."

"A very skilled and knowledgeable doctor. The support of family and friends. Finding other ovarian cancer survivors and sharing our knowledge and experiences. The wealth of information within that network is invaluable."

"Access to great doctors, excellent insurance, family support and the ovarian cancer community."
What has been helpful through treatment and survivorship?

Support from family and friends.
After initial shock, educating myself about ovca
Connection to ovca community
Giving back since I was fortunate to survive,
I don't feel "survivor guilt" but I do feel survivor responsibility

My gyn onc who was instrumental on getting me into my immunotherapy clinical trial.
She always listened to me and answered all my questions.
She was patient, ALWAYS had a game plan and gave me hope.
She made me feel part of the team.
What advice would you give to someone newly diagnosed with ovarian cancer?

- See a gynecologic oncologist
- Get a second opinion
- Find a support group
- Educate yourself
- Walk
- Exercise
- Hydrate
What do you wish you could say to your doctor?

“Thank you for saving my life.”

“I already did: YOU ARE THE BEST!!!”

“Thank you for treating me as an individual and not a statistic. Everyone who faces ovarian cancer deserves the compassionate care that I received.”
What do you wish you could say to your doctor?

“Listen to me and hear what I’m saying.”

“...Be honest with your patients.”

“Listen, understand long term fears.”

“I wish my gynecologist was focused on helping me move forward...”
I appreciate the work that you do. I cannot begin to comprehend how difficult it must be to treat women who are in a fight for their lives every day. The emotional toll must be a weight for you.

Your work makes a difference, and I am extremely grateful that you are dedicating your life to improve my options. Confronting this disease together gives me a sense of well-being. Thank you.

Thank you. Continue to listen to the women about their goals for treatment/life. Take time for yourself so you will still be there for us.
Beyond demographics
# Recap: Progress and Unmet Needs

## PROGRESS/IMPROVEMENTS

- **Increase in length of survival**
- **Surgery**
  - Importance of gynecologic oncologist
  - Optimal debulking and zero residual
  - Primary and neoadjuvant available
  - Robotic surgery
  - Fertility discussions, egg storage
- **Recognition of 2007 Consensus Symptoms**
- **Understanding ovarian cancer**
  - TCGA revealed complexity of ovarian cancer
  - Somatic gene testing for treatment prioritization (guidelines)
  - Site of origin
    - Fallopian tubes (HGS)
    - Endometriosis (clear cell)
- **Hereditary genetics**
  - Discovery of BRCA, Lynch syndrome and other hereditary mutations
  - Discontinuation of gene patent
  - Genetic testing and cascade testing recommendations added to guidelines
  - Opportunity for risk reduction
    - Prophylactic surgery
    - Birth control pills
    - Embryo selection
- **Treatment**
  - Targeted therapies and maintenance
    - PARP Inhibitors
    - Bevacizumab
  - Interperitoneal therapy (survey only)
  - Immunotherapy responses in some
  - Increased acceptance and availability of integrative/complimentary therapies
  - Innovative clinical trials available at some cancer centers
- **Monitoring**
  - CA-125
  - Imaging: CT, PET, MRI, ultrasound
- **Quality of life**
  - Antiemetics
  - Palliative/Supportive care
  - Role of exercise
  - Nutrition
- **Survivorship**
  - Survivorship plans
  - Better information online
  - Access to support groups

## UNMET NEEDS/LIMITED IMPROVEMENT

- Virtually no change in mortality
- Lack of Early detection/Screening
- Resistance to treatment
- Underutilization of advances
  - Genetic and cascade testing
  - Somatic testing
- Disparities
  - Underserved, marginalized populations
  - Socioeconomic, underinsured
  - Rural areas
  - Variations in practice and skills
- More treatments/research needed for
  - Non-BRCA/Non-HRD
  - Rare subtypes
- Cost of treatments
- Long-term side effects
  - Neuropathy
- Lack of Awareness
  - General public
  - General medical community
  - Younger women overlooked for dx
Conclusions

Long-term ovarian cancer survivors listed twice as many advances than unmet needs during the roundtable.

However, the magnitude of impact of meeting these unmet needs (early detection, access to Standard of Care, overcoming resistance) may be quite significant on survival for patients, possibly outweighing the advances made to date.

Overall, LTS are excited about progress, yet frustrated that so much remains unchanged.

Too many advances that have extended survival and improved QOL for some patients are not equally available and accessible to all.
Acknowledgements

• Roundtable and survey participants
• Our own medical teams who made our long-term survival possible
• SGO and professional colleagues who continue to be partners in progress
• Frank Licciardi, MSK PFACQ Co-chair Emeritus and Powerpoint Yoda

Notably missing are the perspectives of long-term survivors and pioneer research advocates who died in 2022.

Mary (Dicey) Jackson Scroggins
Diane Paul

We dedicate this work to them and to all who have advocated in many ways to improve the treatment landscape and journey for others.