A Nurse-Led Care Model to Improve Access to Rural Survivorship Care

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National Coalition for Cancer Survivorship
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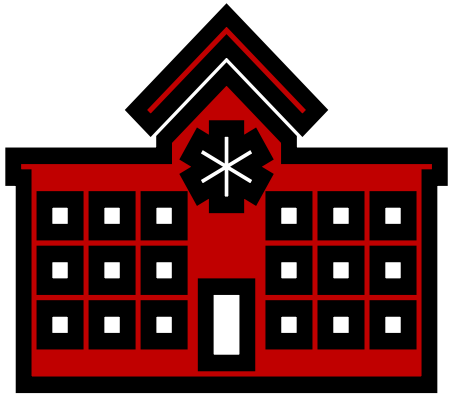
Rural Cancer Survivors

Survivorship phases: acute, extended, permanent

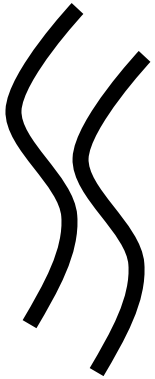
- Longer distance to active cancer care
- Limited PCP education in survivorship
- Lower survival rates, lower quality of life

Mullan, F. (1985). Seasons of survival: reflections of a physician with cancer. *New England Journal of Medicine*, *313*(4), 270-273.

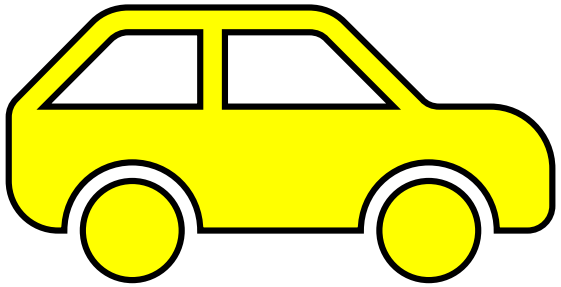
Traveling for Post-Treatment Care

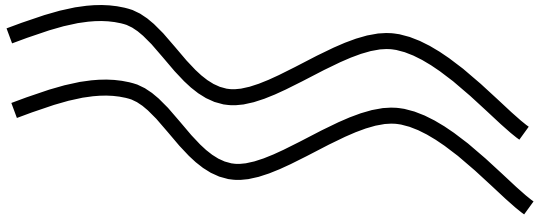


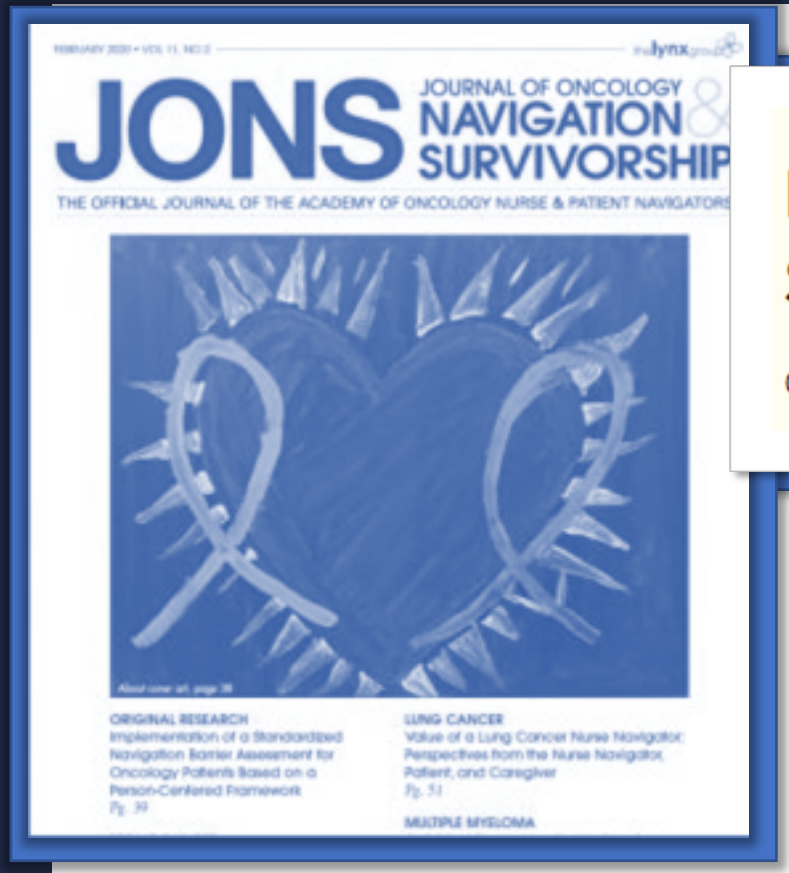
Rural survivors are less willing to travel for supportive care than for treatment *(Lavernge, Pesut, Opie)*



Travel distance is independently associated with more unmet needs and poorer QoL during survivorship *(So)*







Identifying Barriers to Navigation Needs of Cancer Survivors in Rural Areas

October 2015 Vol 6, No 5

- Rural survivors do not know how to access survivorship resources once primary treatment is completed
- Rural survivors do not always have supportive care needs recognized/addressed during treatment

✓ ***How do we connect rural survivors with appropriate care once treatment has concluded?***

Survivors May Not Be Ready for SCP Information at the End of Treatment

- SCPs? *"...oh that pile of papers"*
- At their "end of treatment" appointment, focus on having survived – not what is coming next
- Knowledgeable about *medical* aspects of survivorship.

  ✓ ***Survivorship assessment and education needs to occur at a time distant from the end of treatment***

  ✓ ***Uncoupled from the medical aspects of treatment***

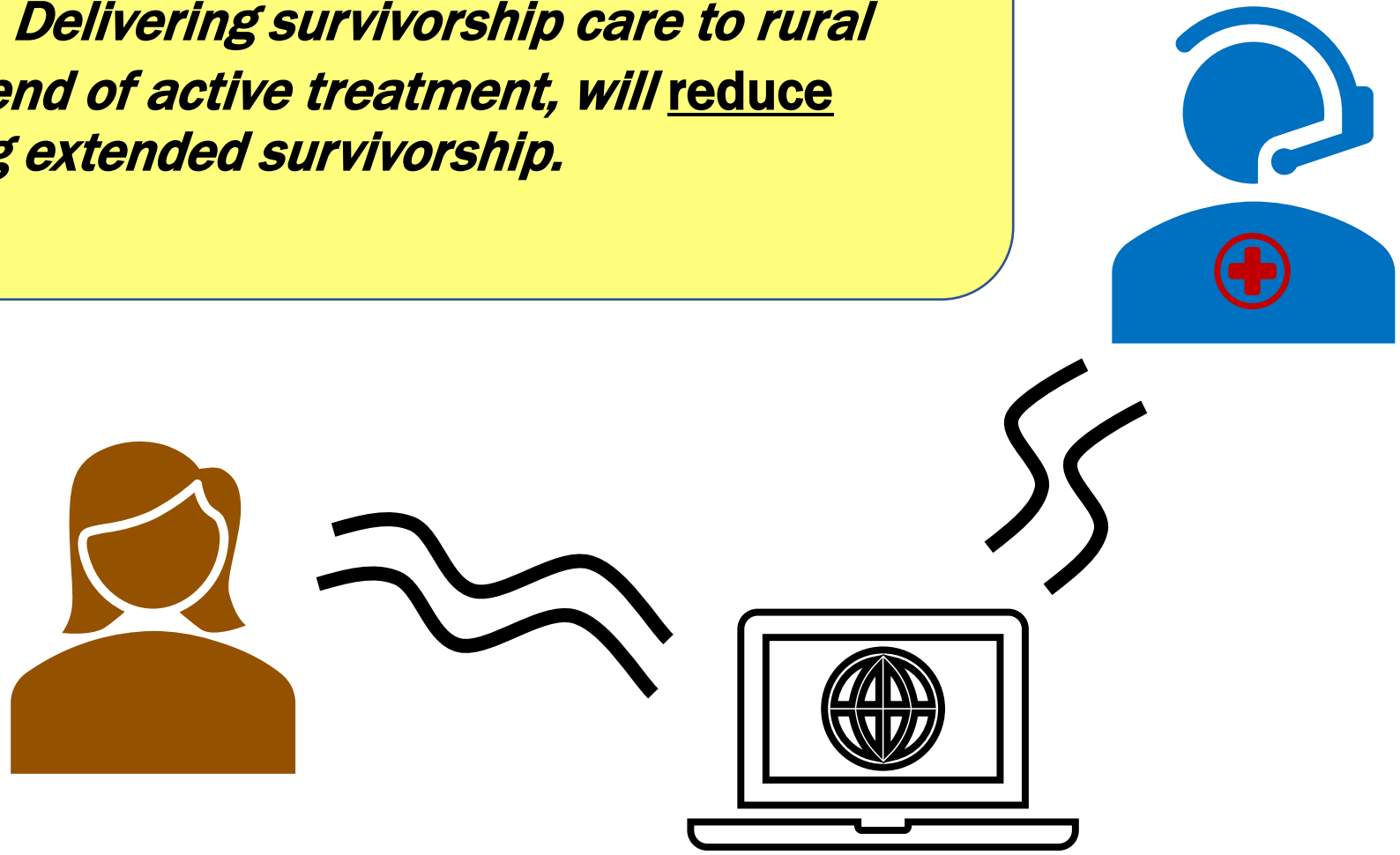
Survivorship Care Plans: Rural, Low-Income Breast Cancer Survivor Perspectives

Pam Baker DeGuzman Kaitlyn Colliton Carmel J. Nail Jessica Keim-Malpass

Survivorship Care Patient Education

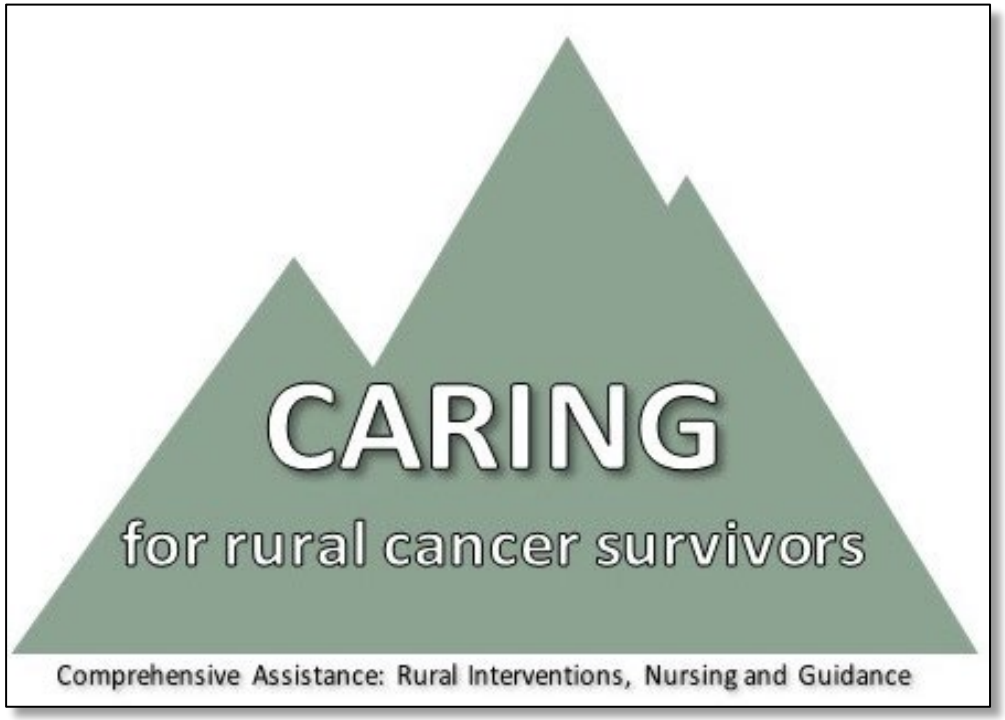
CJON 2017, 21(6), 692-698 DOI: 10.1188/17.CJON.6

Hypothesis: ***Delivering survivorship care to rural survivors after the end of active treatment, will reduce unmet needs during extended survivorship.***



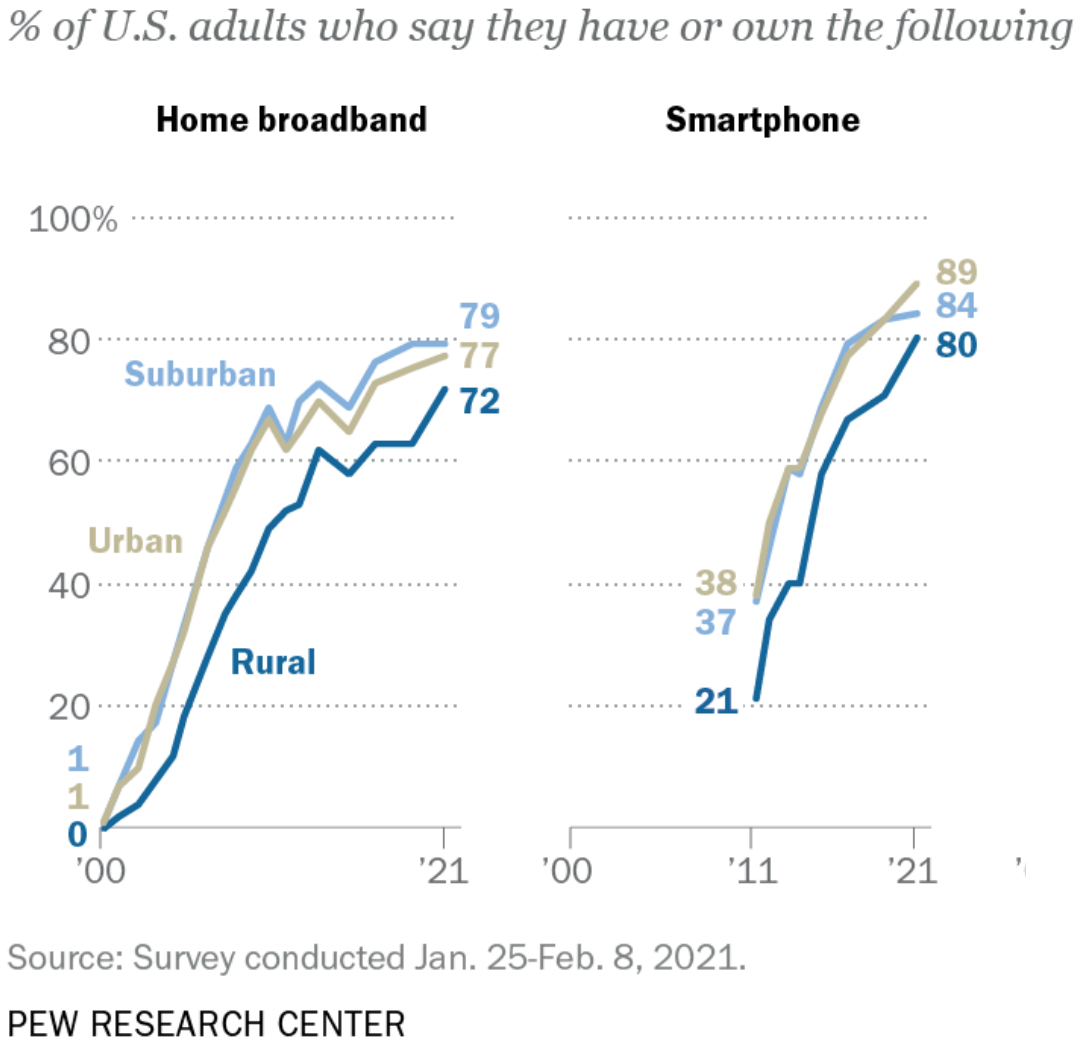
CARING is a telemedicine-delivered nursing visit for cancer survivors delivered several weeks after treatment has been completed. The intervention has three main components:

assessment, education, and referral.



Known Barriers to Telemedicine in Rural Areas

- Rural residents' broadband access
  - Fewer have broadband
  - Fewer places to go if you do not have broadband
  - Less likely to own a smartphone



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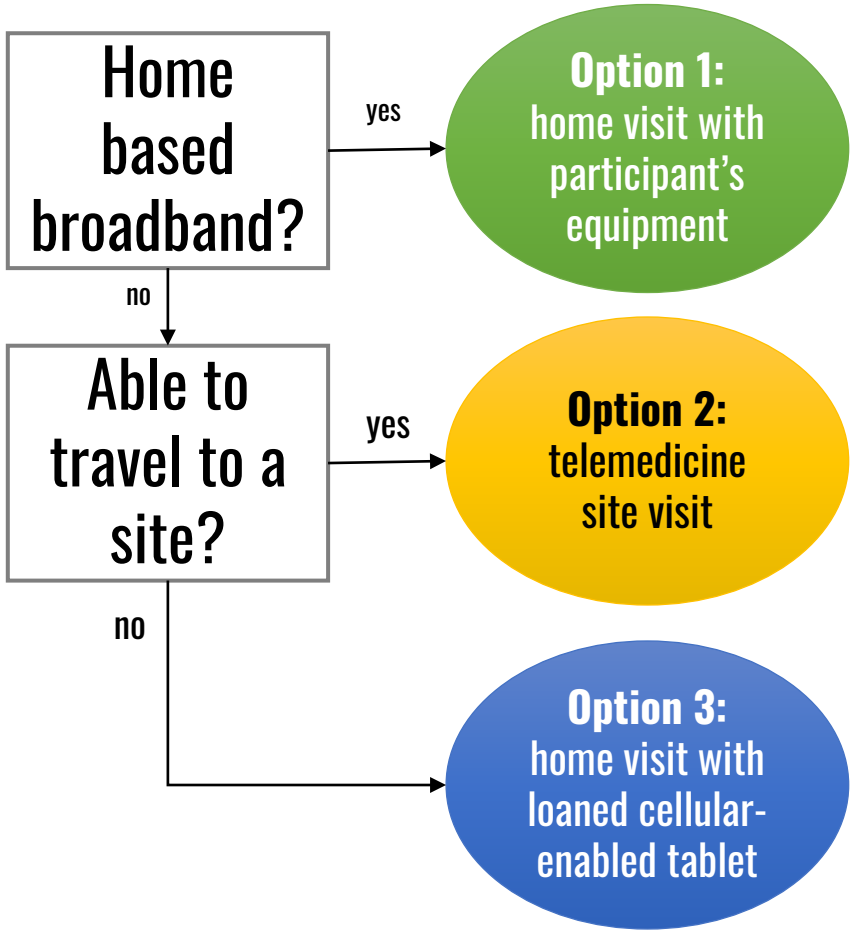
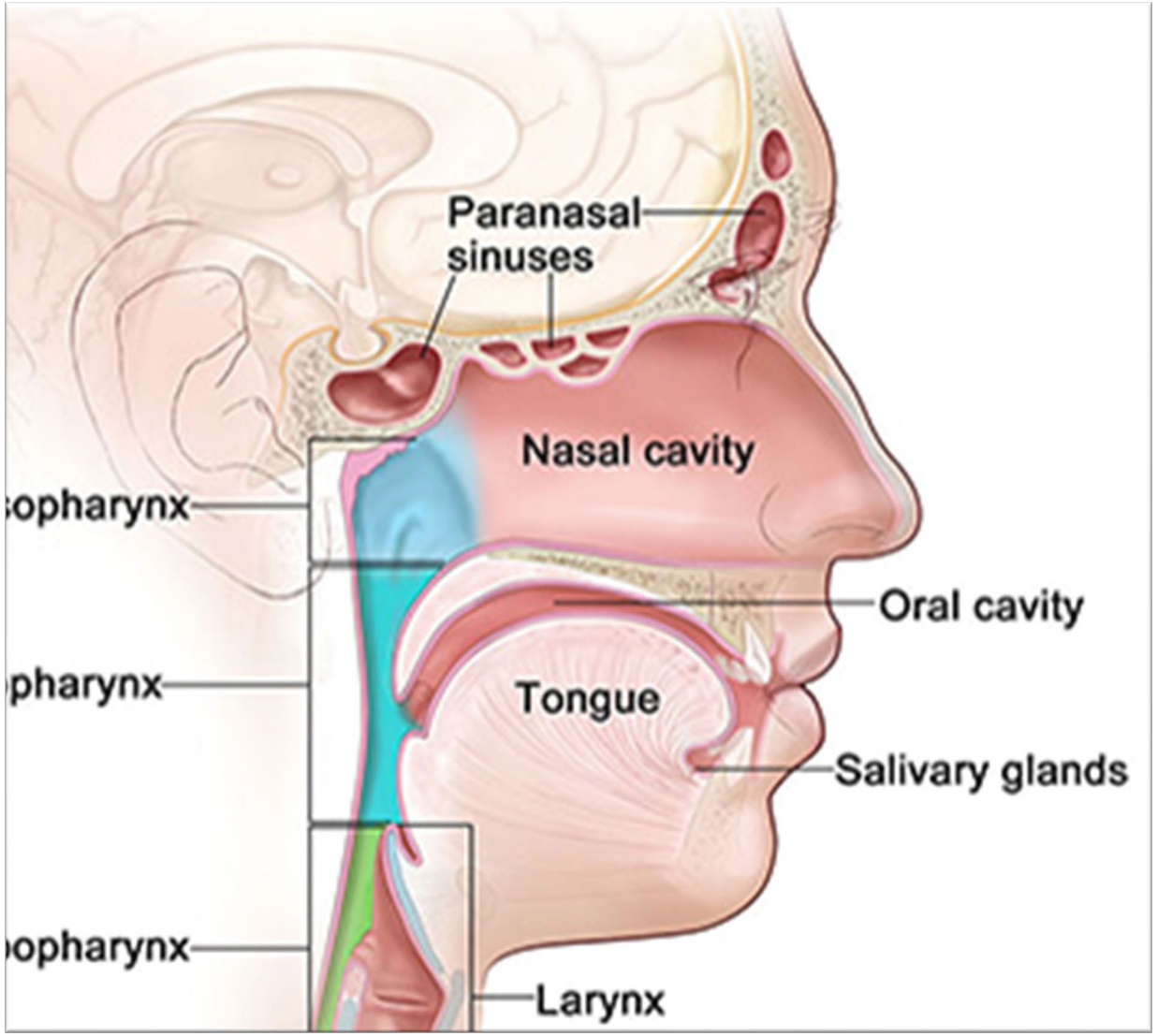
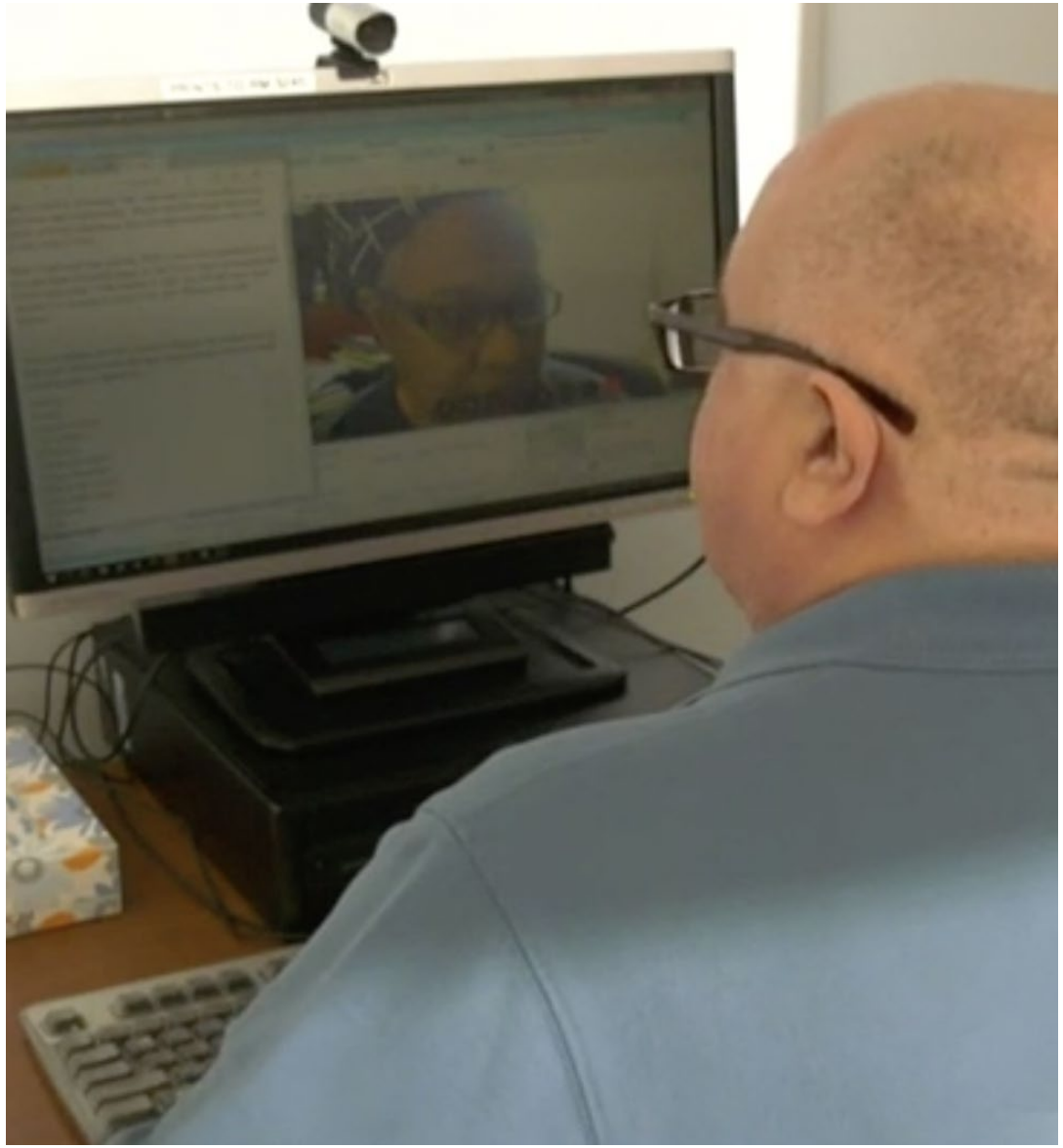


HNC Survivors' Persistent "Unmet Needs"

2nd highest rate of suicide.

- Two-thirds have unmet needs during survivorship
- 3.7 unmet needs per person 4-5 years post-treatment
- Unmet Needs significantly impact HNC survivors' Quality of Life

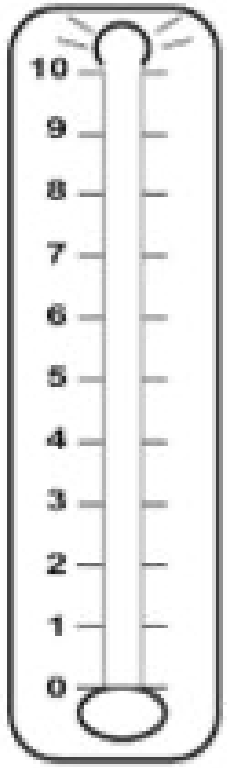




FOR MEASURING DISTRESS

ase circle the number (0-10) that best distress you have been experiencing in ing today.

listress



istress

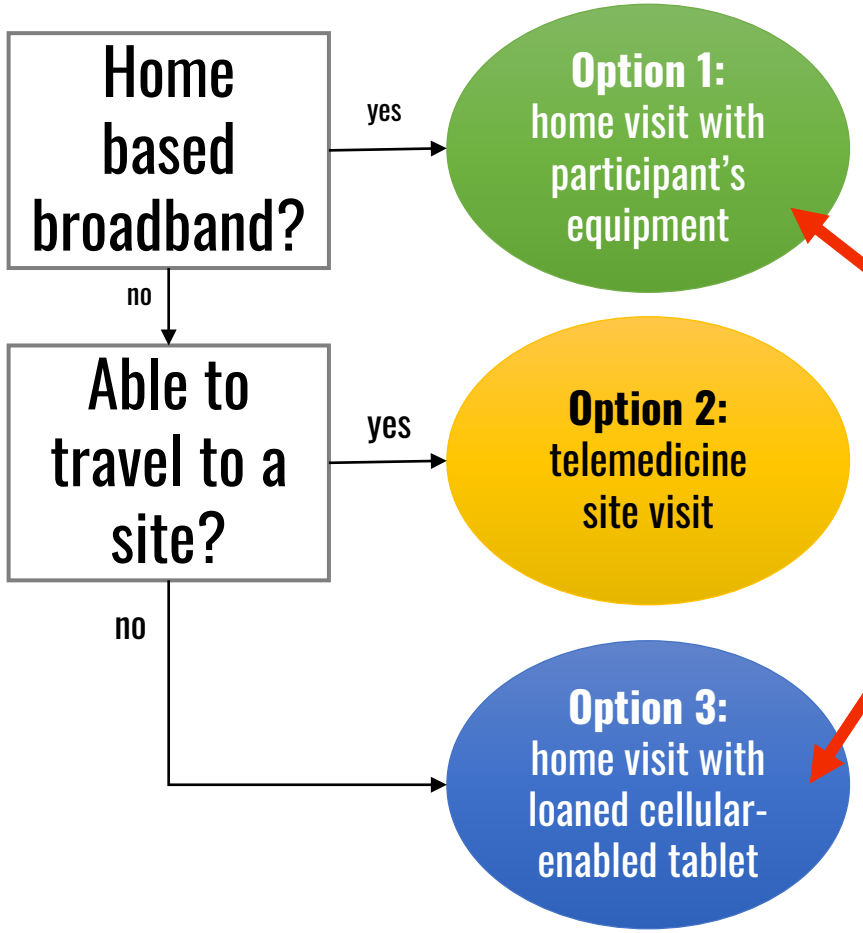
Second, please indicate if any of the problem for you in the past week inc check YES or NO for each.

YES	NO	Practical Problems	Y
❑	❑	Child care	
❑	❑	Housing	
❑	❑	Insurance/financial	
❑	❑	Transportation	
❑	❑	Work/school	
		Family Problems	
❑	❑	Dealing with children	
❑	❑	Dealing with partner	
❑	❑	Ability to have children	
		Emotional Problems	
❑	❑	Depression	
❑	❑	Fears	
❑	❑	Nervousness	
❑	❑	Sadness	
❑	❑	Worry	
❑	❑	Loss of interest in usual activities	
❑	❑	**Spiritual/religious concerns**	

Other Problems: _____

Finding #1

***Digital Inclusion Impacts Telemedicine-even when broadband challenges are overcome**



- Home use of broadband often led to <u>increased</u> distress among participants when they were unfamiliar with technology.

***Digital Inclusion includes both broadband access AND digital literacy/skills**

Finding #1

Digital Inclusion Impacts Telemedicine-even when broadband challenges are overcome

"It was just not connecting! And you know that's just nerve wracking when something doesn't work and you're trying, you know?"

-rural cancer survivor

Published: 11 May 2020

Beyond broadband: digital inclusion as a driver of inequities in access to rural cancer care

Pam Baker DeGuzman ✉, Veronica Bernacchi, C. Allen Cupp, Brian Dunn, B. J. Ferrebee Ghamandi, Ivora D. Hinton, Mark J. Jameson, Debra Lynn Lewandowski & Christi Sheffield

Journal of Cancer Survivorship (2020) | Cite this article

Finding #2

Rural Cancer Survivors with High Distress Refuse Further Intervention

- **90%** had self-identified high distress
- The nurse referred **50%** for further support
  - **Intervention was associated with a 13x chance of a referral!**
- ***But,*** *of those offered a psychosocial referral, fewer than one-third accepted the referral.*

Examination of a distress screening intervention for rural cancer survivors reveals low uptake of psychosocial referrals

Pam Baker DeGuzman, David L. Vogel, Bethany Horton, Veronica Bernacchi, C. Allen Cupp, B. J. Ferrebee Ghamandi, Ivora D. Hinton, Christi Sheffield & Mark J. Jameson

Journal of Cancer Survivorship (2021) | Cite this article

1775 Accesses | **10** Altmetric | Metrics

Finding #3

Reluctance to Accept Psychosocial Help Aligns with Known Rural Social Norms

- When explaining their reasons for turning down further help, rural survivors minimized their distress, and described stigma associated with seeking help, particularly from those outside their immediate family.

> "I don't want to learn [sic] the appearance that as I'm getting older, I am less able to handle my situation, and that's a protection on my part. I try not to view anybody else that way, but I tend to view myself more critical [sic]."
>
> -*rural cancer survivor*

*under review at Journal of Medical Internet Research-Formative

Finding #4

Rural Survivors are Willing to Overcome these Barriers to Discuss Distress with a Nurse over Telemedicine

Telemedicine Satisfaction and Use Questionnaire (scored 1-5)	Mean
A nurse can get a good understanding of my condition during a visit	4.20
My nurse answers my questions	4.20
My nurse deals with my problems	4.27
My nurse engages me in my care	4.33
I can explain my problems well enough during a video visit	4.47
I can always trust the equipment to work	3.00
My privacy is protected during video visits	4.20
The telemedicine equipment is easy to use	3.73
Video visits make it easier for me to contact the nurse	3.73
Video visits are a convenient form of healthcare for me	3.73
Video visits save me time	3.87

***under review at Oncology Nursing Forum**

Finding #4

Rural Survivors are Willing to Overcome these Barriers to Discuss Distress with a Nurse over Telemedicine

- Survivors explained that the biggest benefit of participating in the visit was being able to speak with the nurse about their distress.

> "[I appreciated the nurse] taking the time to ask me the questions. And you know, identifying with my needs…It's good to have someone ask these kinds of questions."
>
> -*rural cancer survivor*

*under review at Oncology Nursing Forum

Finding #5

A nurse-led telemedicine intervention reduces survivors' unmet emotional needs.

Change in Unmet Needs (n=11) **Negative number indicates reduction in unmet needs; scale is 1-4*		
	mean	sd
Overall	-0.24	0.46
Information Needs	-0.24	0.84
Work and Financial Needs	-0.02	0.22
Access and Continuity of Care Needs	-0.21	0.37
Coping, Sharing and Emotional Needs	-0.39	0.81

* *in press* at Oncology Nursing Forum

Conclusions

- Consider digital inclusion, not just broadband accessibility when connecting to rural survivors over telemedicine.
- Rural survivors can benefit from discussing distress with a nurse over a virtual connection.
  - Social norms may prevent willingness to speak to other members of the healthcare team
  - They will openly discuss distress with a nurse
- Targeted identification and discussion of distress with a nurse can improve unmet needs.

Next Steps

- Testing *self-affirmation* intervention
  - Will this improve uptake of psychosocial referrals?
- Incorporating *warm hand-off* to social worker
  - Ensures that patients who accept are more likely to connect to help.

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