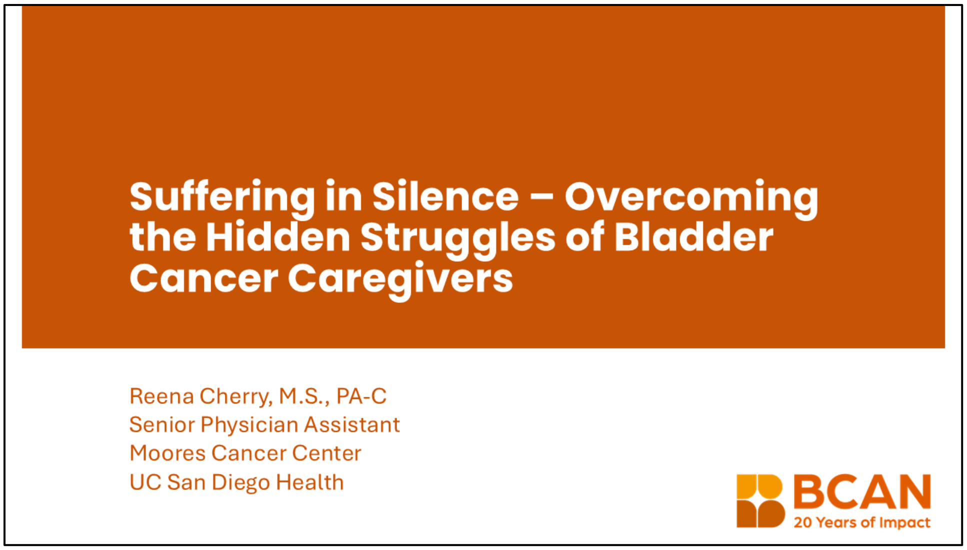


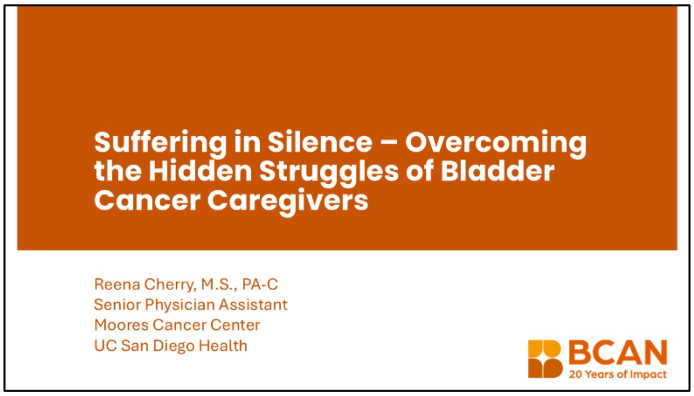
Suffering in Silence – Overcoming the Hidden Struggles of Bladder Cancer Caregivers

Reena Cherry, M.S., PA-C
Senior Physician Assistant
Moores Cancer Center
UC San Diego Health

BCAN
20 Years of Impact

Patricia Rios:

Today's topic is Suffering in Silence- Overcoming the Hidden Struggles of Bladder Cancer Caregivers. Caring for a loved one with bladder cancer is an incredible act of love, but it can also be overwhelming, exhausting, and isolating. Caregivers spend hours each day helping with medical appointments, treatments, and daily tests. Yet, their struggles often go unnoticed. Many feel guilty about their own stress and emotions, leading them to suffer in silence.



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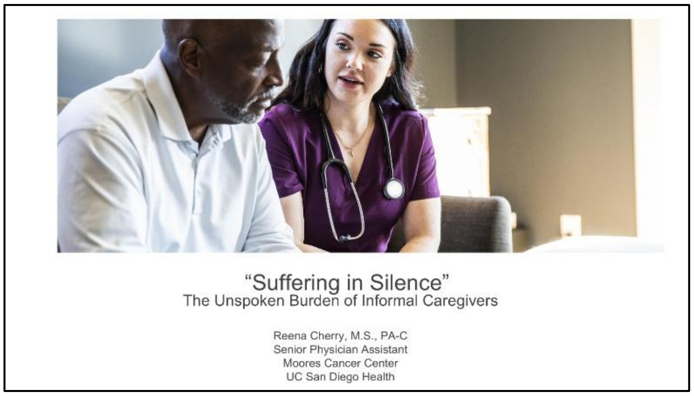
BCAN is delighted to have Physician Assistant Ms. Reena Cherry, senior physician assistant from UC San Diego Health, who will highlight her research about the unique challenges faced by bladder cancer caregivers. Reena has a distinguished career spanning 24 years serving the oncology community. She has worked as an expert clinician at two of the nation's most prestigious healthcare institutions, MD Anderson Cancer Center in Houston Texas, and UC San Diego Health, in her beloved hometown. With a deep commitment to compassionate patient care, Reena also dedicates her time to supporting the needs of informal caregivers who are an essential component of our healthcare system. Reena received her Bachelor of Science degree in Psychology from Spelman College in Atlanta, Georgia, and her Master of Science degree in physician assistant studies at Baylor College of Medicine in Houston, Texas. I am now going to turn the webinar over to Reena, who will highlight why caregiving can feel so difficult, the emotional toll it takes, and suggest practical ways to find support and balance. Reena, thank you for joining us.

Reena Cherry:

First, I want to say thank you, thank you, to BCAN for inviting me to speak this evening and for just showing...um, creating a space really for us to talk about caregiving. Um, I'm just so excited that BCAN found value in this topic. It is, I’m very passionate about it as I hope you'll see, um, but our caregivers tend not to have a safe space to talk about these things and so I just am so appreciative that BCAN has given us a platform to do this. Um, and I also want to thank all of you so thank you for being here together on this webinar, and, um, I hope it's something that I have to say tonight will be of value to you.



“Suffering in Silence”
The Unspoken Burden of Informal Caregivers

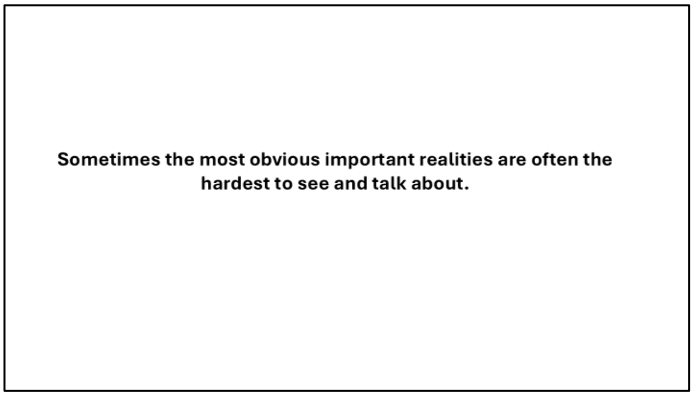
Reena Cherry, M.S., PA-C
Senior Physician Assistant
Moores Cancer Center
UC San Diego Health

As Patricia said, I've been an oncology PA for over 25 years, and, um, I've worked at fantastic organizations and we've done an extraordinary job supporting patients, um, but over the years, I really did see a huge void in our support and really acknowledgement of caregivers, and it just kept gnawing at me that there were these um, extraordinary people who, in many ways, are the backbone of bladder cancer and backbone of healthcare in general, and we weren't acknowledging them or even trying to figure out how we could support them better. So, this talk was really born out of a desire to shed some light on the extraordinary work that caregivers do, um, and also start to talk about some of the ways that caregivers struggle, and almost across the board, all caregivers do struggle. So, um, I'll start today… well what we're going to do is I'll give you some information about caregivers in the United States, so I'll share some data with you about that. We're going to dig into what exactly caregivers are doing on a daily basis to support our bladder cancer patients, I'll talk to you about why caregivers tend to struggle. Um, so we'll get into some of the feelings and emotions behind caregiving, and then I'll talk about ways we can help.

So, to start, I'm going to share a parable with you. Here goes. So there are these two young fish swimming along, when they meet an older fish swimming in the other direction, who nods at the fish and says, “Morning boys, how's the water?" And the two young fish keeps swimming along until finally one of the fish turns to the other one and says, "What the heck is water?" Now the meaning behind the parable is this,

Reena Cherry:

Sometimes the most obvious important realities are the hardest to see and talk about. And when I heard this, I immediately thought about caregiving. We all know caregivers. We have a peripheral idea of what it is they do to support our patients, but this is a very difficult topic for us to talk about.

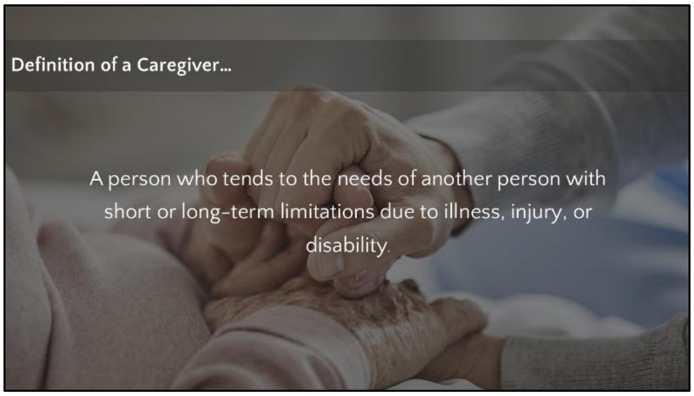


Sometimes the most obvious important realities are often the hardest to see and talk about.

And one of the reasons it is so difficult is that in order to have an authentic conversation about caregiving, it requires that we acknowledge certain feelings and thoughts that we have, and it requires that we acknowledge certain physical and clinical realities about our loved ones that we're supporting that we wish were not so. And in order to talk about those things, we have to move into a vulnerable space. And I've learned over the years that most human beings avoid feeling vulnerable at almost all costs. And since the topic of caregiving requires that we be vulnerable, we tend to sidestep it. So, again today, I'm going to try to help us peel back those layers so that we can create a safe space for us to talk more openly about this important subject.

Reena Cherry:

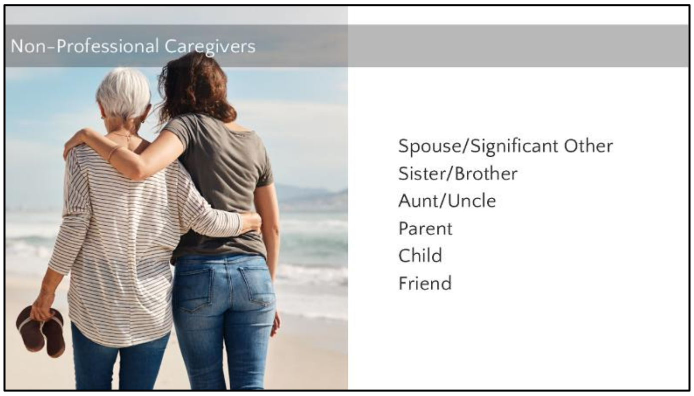
So we'll start with a definition of a caregiver. A caregiver is a person who tends to the needs of another person with short or long-term limitations due to illness, injury, or disability.



Definition of a Caregiver…

A person who tends to the needs of another person with short or long-term limitations due to illness, injury, or disability.

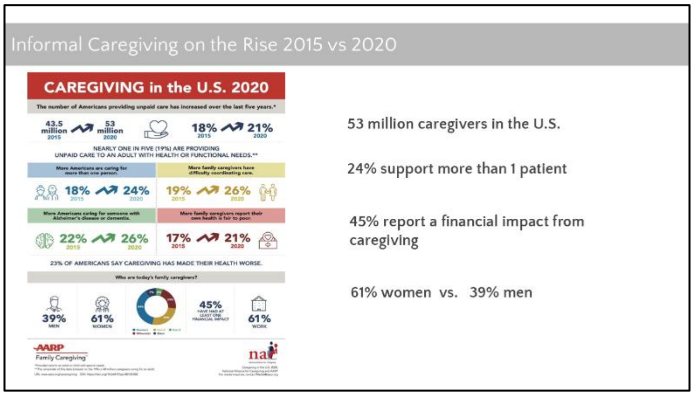
Reena Cherry:


Non-Professional Caregivers

Spouse/Significant Other
Sister/Brother
Aunt/Uncle
Parent
Child
Friend

And caregivers are our… you know there are many times significant others. They're sisters, brothers, aunts, uncles. Um, parents, um, are having to take care of one another. Um, children are having to take care of their parents, et cetera. Friends also provide a lot of support and care for our bladder cancer patients.

Reena Cherry:


Informal Caregiving on the Rise 2015 vs 2020

53 million caregivers in the U.S.

24% support more than 1 patient

45% report a financial impact from caregiving

61% women vs. 39% men

Now, when I was doing research about caregivers, I had the fortune of stumbling upon the National Alliance, um, for Caregiving. The National Alliance for Caregiving is a coalition of non-profit organizations that came together in about um, 1996 to amass some of the most accurate data that we have about caregivers in the United States, and also in an effort to amass some of the best resources and research opportunities we have to continue to study and determine ways that we can support our caregivers.

Now, the National Alliance for Caregiving partners with AARP, and they conduct a survey once every five years or so. So, their most recent survey was conducted in 2020, and they compare that data against, uh, the survey they did in 2015. Now, as an aside, I've actually reached out to the National Alliance for Caregiving, and they are um, assimilating data right now, um, about where caregiving stands in 2025, and we should have that information available to us in 2026. So, hopefully, I'll be able to present that information to you early next year. But as of 2020, here were the highlights of their research. Number one, there were approximately 53 million caregivers in the United States and that was up from 43 million caregivers in 2015. So, caregiving is definitely on the rise.

Number two, 24% of caregivers reported that they support more than one patient. So I want us to be um, clear. Most of us, when we think about caregivers, we assume a one-to-one ratio, and many times that's not the case. There are many caregivers who are supporting more than one patient, which is an enormous undertaking, and I hope you understand how enormous that is um, in a little bit. But, um, many caregivers are supporting multiple patients. Third, about 45% of caregivers reported a financial impact from caregiving. So, there are many, many caregivers who have to reduce their footprint in the workforce or leave the workforce entirely in order to absorb their caregiving responsibilities. And that's obviously a significant impact for the individual caregiver, but it also impacts their families. Um, and so, this is a significant uh, comes a lot of times uh caregiving comes at a significant financial cost to the caregiver. And last, the data showed that as of 2020, 61% of our caregivers in the United States were women versus 39% who are men. Those are some of the big highlights from the 2020 survey.

Reena Cherry:

Caregivers in Action

Any Life Threatening Illness:

- Surgery
- Radiation
- Chemotherapy
- Dementia
- Diabetes Mellitus
- Kidney Disease
- Cardiac Disease
- Stroke/Traumatic Brain Injury
- Neurologic Disorders

All right, so when we look at caregivers in action... We're obviously focused on our bladder cancer patients, but I wanted to give you a scope of where caregivers come into play um, across the medical landscape. So, um, certainly we have caregivers who are providing support um, before and after surgery, during radiation, and before and after chemotherapy for our oncology patients. However, caregivers are also significantly in need when um, we start to talk about the dementia space, that is an ever-growing um, population of people, unfortunately, and caregivers are really um, really having to step up to the plate to support those patients.

Certainly patients who suffer from end-stage diabetes, um, end-stage renal disease, um, there are patients who have significant cardiac issues, end-stage congestive heart failure, patients who have had stroke or um traumatic brain injury, and also you know, patients who are suffering from a neurological, a neurologic disorder such as Parkinson's, so this is not an inclusive list but certainly gives us a broad perspective of where caregivers are supporting patients across the board.

With respect to our bladder cancer patients, caregivers are at the forefront and they're with the patient from the very beginning of this diagnosis. So certainly with patients who are undergoing um, their initial cystoscopies and bladder biopsies. Um, we have caregivers who are supporting patients throughout BCG installations, which as we all know can last for weeks to months. Um, certainly patients who need um, surgery and/or radiation to treat their bladder cancer, caregivers are obviously in play. And then I also wanted to mention little things that we tend to overlook um, where caregivers are a tremendous support. So many of our patients have Foley catheters. We have many patients who have ostomies. We have many patients who have percutaneous nephrostomy tubes or tubes that go into the kidney and drain the kidney. These are all things that need to be managed and monitored, and caregivers are doing this every single day.

Um, I would be remiss if I did not mention emergency room visits. So, emergency room visits happen frequently. Obviously, the, you know, our patients who are acutely ill sometimes have multiple ER visits. And just to put a finer point on it, an ER visit can be uh, multiple hours. Sometimes we have patients who sit in the ER for six to eight hours at a time, uh, and ERs across the country are packed. So, there are patients who spend days in the ER before they are given a bed and admitted into the hospital. And we should also be present to the fact that caregivers, you know their, the intensity of care they're providing increases in the days leading up to that ER visit. So, most patients become ill at least two to three days before they end up in the emergency room and the caregiver is having to care for the patient during that time and make decisions about, "Is it appropriate to take to the ER? When do I take to the ER? What are the symptoms," calling the clinical care team.

So, the intensity of the work they do rises, the patient gets to the ER, and then that care continues throughout the emergency room stay, throughout that inpatient stay, and then in the days to weeks afterwards. So ER visits is huge. Um, certainly, patients who are, you know, more acutely ill who require support in a skilled nursing facility, um, caregivers are still very much involved. And then unfortunately for patients who need hospice or at the end of life, that is one of the most, uh, physically intense and emotionally intense periods of time for caregivers. This gives us, I hope, a better idea of what our bladder cancer caregivers are doing for our patients.

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