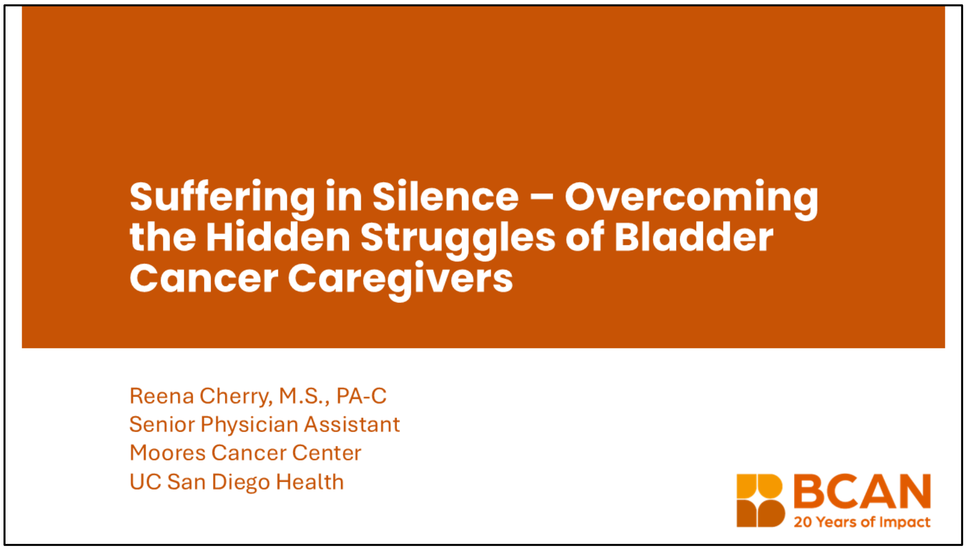

Suffering in Silence – Overcoming the Hidden Struggles of Bladder Cancer Caregivers

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BCAN
20 Years of Impact

Patricia Rios:

So with that, I'm going to, uh, lead us into our Q&A. Reena... um, well, one I, again, thank you for, for giving our caregivers a voice, uh, during this webinar. I, I, was curious, you know you talked about the different... um, how you create a space, you recognize caregivers, um, and you asked the question what, what, keeps them up at night? And I'm sure there's many responses that you get, but I wonder if there's a common theme that comes to mind that you might be able to share with us.

Reena Cherry:

Yeah, I think, I don't know that there... you know, caregiving, the other, um, challenge with it is that, um, the caregiving journey is really different for every family and every, um, every caregiver. So, there are different, um, pressure points for every caregiver. I think, again, as I sort of touched on, I think the unknown in general is really eats away at caregivers because they're frantically trying to strategize and plan. And so, I think the more we can give them an idea of what's coming down the road and what they need to worry about and what they don't, I, I, think it's really unhelpful for us to say, "Hey, don't worry about it, don't worry about it," um, they're going to worry. They're going to worry. So part of what, um, I try to do is help to them prioritize. So, um, like, as an example, many caregivers are obsessed about making sure their loved one eats. This is, this is, actually a common one. "He's not eating. She's not eating." And, and, they're really, really intent on, on, feeding because when we, as human beings to nourish somebody is to give them food, that's one of the things that we do as human beings is we want to nourish. But if someone is moving through systemic chemotherapy, they're going to have a very, very low appetite sometimes no appetite, and what caregivers sometimes don't understand is that it is extremely difficult to eat when you have absolutely no appetite. Most of us on the call have some sort of an appetite. We might not feel like eating now, but our appetite exists. So when patients are void of an appetite, it's really hard for them to eat. And so, one of the things I'll tell caregivers is, "listen, don't, like don't, exhaust yourself whipping up three course meals during chemotherapy. Like he's probably not going to want to eat that much."

I don't care how good of a cook you are, and I don't care how big the meal is. So, maybe just choose one or two things, if he says he wants to eat like a bologna sandwich a day, just make a little bologna sandwich. You don't have to make a huge dinner meal. So just kinda helping them understand what is more realistic um, and, and what they don't really need to do. So, eating and appetite is just one example. But again, I think giving them an idea of things that they don't have to worry about now, things that they we will definitely address later to help them shift and prioritize what's on their plate is really important.

Patricia Rios:

Yeah, yeah, and I think, uh, I think you mentioned, um, something very valuable is that you know, as caregivers we want to do everything we can to be able to show our love, and, and, um, whether that includes you know, uh, feeding them, uh, and you know and so I think uh, um, uh, perhaps, like, the, the, the, the, the suggestion may be also to you know um, uh, the, the little things count, right? It doesn't have to be, uh, um, you don't have to go above and beyond, um, with some of the stuff and, and really understanding kinda what the loved one is going through, um.

Reena Cherry:

Yeah.

Patricia Rios:

So, with, let's switch gears to self-care cause I'm, I'm curious to hear, because one of the things that I hear about a lot with caregivers is, is, burnout, um. And, um, oftentimes I think um, caregivers, may not realize that they're suffering from burnout. Are, are, there any specific signs that, um, you can share with us that, um, caregivers should be aware of, um, that they may be experiencing burnout and how to get help?

Reena Cherry:

Yeah, so that's, um, that's a huge, that's a huge topic, um, I think that, and when, when I, I work with caregivers one-on-one, burnout is, it's really hard to avoid it, but I think there are certain ways that caregivers can slow it down and help try to weave in some self-care as they go. So, one of the challenges is convincing caregivers that it is okay for them to take time to care for themselves. Most caregivers do not feel entitled to do this. And so their mindset is, "If I'm a good caregiver, all of my energy and effort goes to the patient, 100% of it." And they go all out for the patient all day every day, and they will not give themselves permission to care for themselves. And that is a very fast way to burnout. So what I encourage all caregivers to do, I'm officially giving every caregiver who watches this permission to do this, is to choose one thing that they do that makes them feel replenished or revitalized or rested or more present and relaxed.

It can be anything. It can be sitting quietly in a corner. It can be reading a book. It can be journaling. It can be knitting. It can be playing cards with your friends. It can be anything. And I will encourage them to carve out... I would love for them to carve out 20 minutes, but if I have to settle for 10 or 5, I'll do it, but they carve out 10 to 20 minutes a couple of days a week to do this for themselves. And that time has got to be protected time. That is the time for them. It's not for the patient, it's not for their kids, it is for them. So I coach them to set a hard boundary around that time, and I'd love for it to be every day, but that's unrealistic for a lot of caregivers, but it's a hard boundary and it's something they can look forward to that they do for themselves. And when, when we do this for ourselves we tend, it's like filling your own bucket. When you do this, you fill your own bucket and then you're really in a much better headspace to then move forward and help you know the person that you love. So, that is something that I really coach caregivers to do, and I encourage all caregivers to do for themselves, create space. Yeah.

Patricia Rios:

Thank you. You remind me of a, of a, quote I read somewhere that says, "Taking care of yourself is part of taking care of others."

Reena Cherry:

Yes.

Patricia Rios:

So that's, um, a valuable tip. On your presentation, you used the word informal caregiving, and that is the first time that I've heard informal part as part of caregiving, um, it, which led me to, to, wonder is there a formal caregiving? That is, where did that come from?

Reena Cherry:

There is. So there are two categories of caregiving. There are formal caregivers. Formal caregivers are, um, typically medical professionals who have got received training, a license or certificate to give care to a patient, um, and we are paid to do so. That's a formal caregiver. So if you've moved through any sort of a formal education process, received a license or a certificate or graduate degree, and you care for a patient and you do so professionally, that's formal caregiving. Informal caregiving is essentially everything else. They are, um, people who do not hold a degree, typically, um, who don't have medical training, who are providing medical support for patients at home and who are not paid to do so. Those are informal, caregivers and I stress not paid to do so because as I mentioned in my talk, um, there's a significant financial impact that goes along with caregiving and there's a financial impact just in general. Just supplies and the gas going back and forth and the parking and all of these things that caregivers absorb. And then, um, as we talked about, many of them are having to reduce their footprint in the workforce or leave an entirely in order to assume their caregiving tasks. So, um, It's a really is quite a significant financial, um, impact that caregivers have to absorb.

Patricia Rios:

Absolutely. And from my understanding, in some states they, they, recognize that and so there are some caregiving or caregiver reimbursement programs. Are, are you familiar with that? If so, can you speak to that?

Reena Cherry:

Yeah, I'm not familiar with, um, what's available state to state. And sadly, actually, I've not looked into this. I'm in the state of California, um, but there are some reimbursement programs available. I think those are you know specific. So, if you do qualify, um, you may be entitled to, um, some type of reimbursement. But that's again, that's a state to state difference. And will take some digging, of course, and as we talked about, phone calls, follow up, et cetera. But I do think that, um, in some instances there is some financial assistance available. I just don't know how long that financial assistance, um, will cover that caregiver. And I certainly... um, I don't know the numbers, but I don't think it will, uh, unfortunately, absorb all of the financial, um, implications for that caregiver.

Patricia Rios:

That's correct. But if you're interested in learning more about those, I think it'd be interesting to look, to check with your local, um, health program to see, you know, what it covers and...

Reena Cherry:

I think if you go to the state, um, the state government website, usually you're able to sort of navigate and you can pretty quickly find, uh, tabs if there are any resources available. Those should be listed there for, um, for the patient.

Patricia Rios:

Okay. Thank you. Thank you for that.

Reena Cherry:

For the caregiver. Excuse me.

Patricia Rios:

Yeah, uh, the caregiver. Yes. And, and so, so, you, uh, okay so you talked about and defined the informal formal caregiving. Does respite care fall under formal caregiving, and um, how would you define that?

Reena Cherry:

Respite care... Are you asking if it's available for informal caregiving or what, um, can you clarify your question?

Patricia Rios:

Yeah, one, can you explain what respite care is and um and, how to how, can one tap into that kind of resource?

Reena Cherry:

Yeah, so respite care, I think, would be, um, an extraordinary resource for caregivers. Many caregivers, again, when they find themselves in these high intensity situations, that's what they need is respite care that they can, that they trust um and that they can count on. And I don't know of any, um, 100% reliable respite care resources. Certainly, there are private pay, uh, individuals who will come in and provide that sort of respite care, uh, for the patient, but that tends to be incredibly expensive. So, it's one of the things that... I know the National Alliance of Caregiving is looking at, um we, but we do need much more, um, options for caregivers and we need respite options that are affordable. So there are respite options out there. There are um, private, um, companies and organizations that provide this type of care, but the financial impact of that is significant. I will also say this though, um, you know, I've known caregivers that have, um, money and resources and have almost around-the-clock, um, private care for the patient and those caregivers are still overwhelmed. That's why I spent so much time talking about how overwhelming this is, is, that I really haven't seen a difference in the level of overwhelm, based on resources and money available. I have seen caregivers who really don't have a lot of resources, they don't have financial resources, and they are really struggling. And I have seen the other spectrum where there are caregivers who have access to financial funds and private care, and everyone across the board is completely overwhelmed. But I certainly do think we need to do better and we need to do more at providing resources. I'll certainly do some, some digging, um, and if I come across any really good reliable resources, I'll share them with you and you can share them with the BCAN community.

Patricia Rios:

Absolutely, and, uh, um, there, there was a question in the chat, uh, about, uh, creating a space, uh, for caregivers, uh, in the future, um, and for particularly for bladder cancer caregivers, um, and the answer is yes. BCAN is definitely looking into how else we can, um, better support, um, caregivers through, through, their journey of caregiving. So, stay tuned for, that. And there is another question that came in from one of our, uh, attendees, Reena, um, and this question, um, this person's asking, "How do you distract yourself from thinking about caring for the patient while you're looking after yourself or working or relaxing?" That's a very good question.

Reena Cherry:

Yeah, it's a very good question. I think, I think, it takes practice. I think that the more you create time and space for yourself, and I think talking to the patient also, so, is really helpful. When you say, "I really want to be the best caregiver, spouse I can be for you. In order to do this, I have got to carve out a small amount of time for myself. And I wanted to talk to you about this because, I don't, I don't want to feel guilty, and I don't want you to feel like I'm not focused on you, but in order for me to fully engage in my care for you, I have to create a small space for myself." I think most patients would understand that. And then I think it just takes doing it consistently. That's why I love having people do it as consistently as possible so I'd love for, for, caregivers to do this every day, but, um, I think consistency is the key. And then I wanted to add one more thing. I know we're coming to time, but, um one of the ways that I think we can really help support caregivers is that we do have to understand vulnerability. And my comments about how vulnerable it is to be a caregiver, I hope resonated with everyone. Most people when they are in a situation of need are not willing to be vulnerable enough to reach out and call for help. If you think about the times when you yourself have felt like, "Oh my gosh, I'm totally overwhelmed. I don't know what I'm going to do." Most of us are reticent to ask for help. And we're reticent because we don't want to feel that vulnerable. So we cannot, as a community of people who support caregivers, we cannot expect that caregivers are going to pick up the phone and call us and tell us they need help. They're not going to call. They're not going to call because typically they don't want to be a burden and they're not going to call because it is just an incredibly vulnerable, um, thing to do. And so, we have to engage with the caregiver. We have to be in the driver's seat. We can't sit back and say the famous words, "Call me if you need anything." Call's not coming. We have to reach out to them. And if we can do it and really think through... I encourage people to really think about how you can engage. You don't have to do it like your neighbor would do it. If you don't cook well, don't offer to bring meals if that's not your thing. But really think about how you can intentionally engage with that caregiver.

It might be a text message once, once, a week. It may be you know going over and physically just knocking on the door and saying, "Hey, I was thinking about you. I've got about 20, 30 minutes. Can I help?" It may be offering to do a little laundry for them once a week. But we have to go to them and we have to bridge that gap because waiting for the overwhelmed caregiver to call and tell us, "Hey, I'm overwhelmed." We're going to miss, were going to miss them and so that's really another take home that I wanted to highlight is that we really do have to make the effort and we have to really go, um, we have to go to them.

Patricia Rios:

Yeah Reena, this was a very, uh, powerful discussion. And, uh, um I certainly, um, uh, took, I'm certainly going to learn how to you know be more courageous, um, by being more vulnerable. And, and, and, I hope all of our caregivers who are listening today also feel empowered to, to, feel more vulnerable.

I, I, do want to mention a couple of things before we end. Aside from this webinar being available on our website two weeks, um, from today, we also have a, um, support line, um, that is in, uh, partnership with CancerCare and staffed by oncology social workers. And that's a resource for all of our caregivers. If you just need someone to, to, listen, someone to talk to, someone to walk you through different resources in your own community, that is available to you for free. The, the information is in the chat. We also have, uh, um, as part of our peer-to-peer program Survivor 2 Survivor, we have a, a, network of caregivers who are available to, to, um, walk and, and, talk to you through their journey. If you need to talk to someone, um, as well, we can, we can, make a match. And the information on that program is there too. If you'd like to volunteer and, and help and we be matched with another caregiver, um, as part of that program, that is also an option and we invite and encourage you to do that. And with that, I want to really thank, um, uh, Reena for, for, bringing this, this, conversation to, uh, us this evening, um, giving us some very, um, practical and powerful messages, um, and help, and help giving us opportunity to reflect and um, also empowering us to, to, uh, to, take care of ourselves, uh, and to be courageous by being vulnerable, uh, and, uh to, to, um, say that we are here for you and we'll be reaching out to, to, um, to, tell you that we're here and see how we can help you. So, with that, Reena, thank you so much.

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