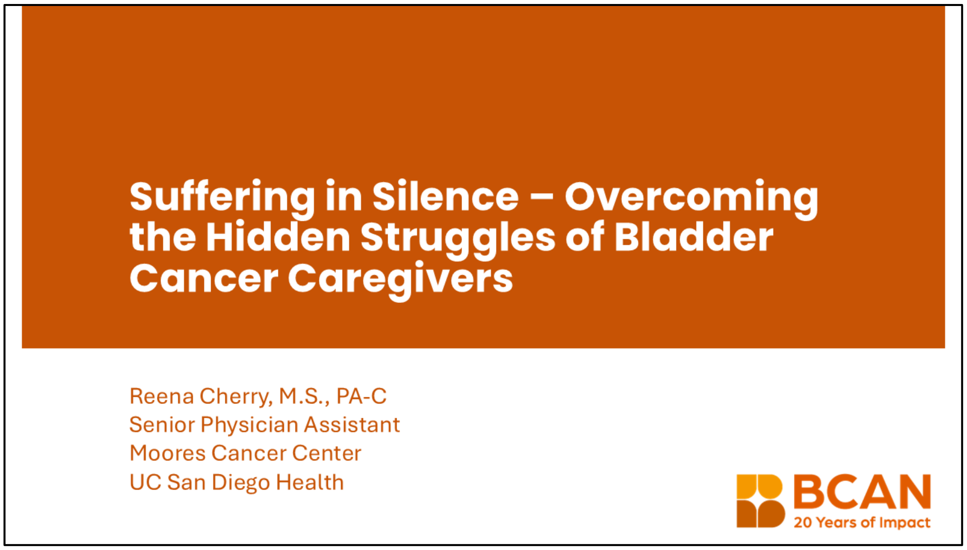

Suffering in Silence – Overcoming the Hidden Struggles of Bladder Cancer Caregivers

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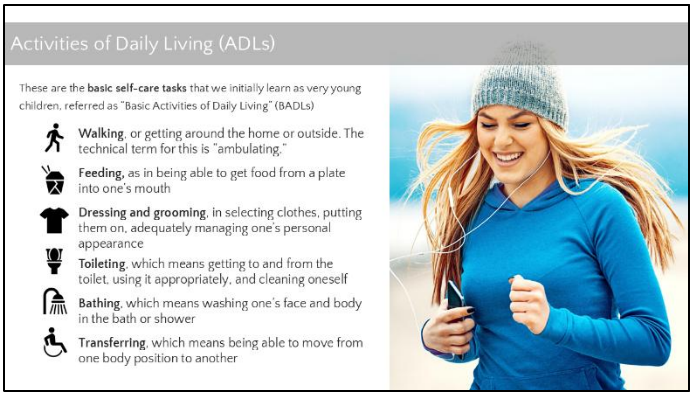
BCAN
20 Years of Impact

Reena Cherry:

Okay, so when we talk about and start to peel back the layers of what a caregiver does on a daily basis, I wanted to share with you the way clinicians initially evaluate how well a patient is doing.



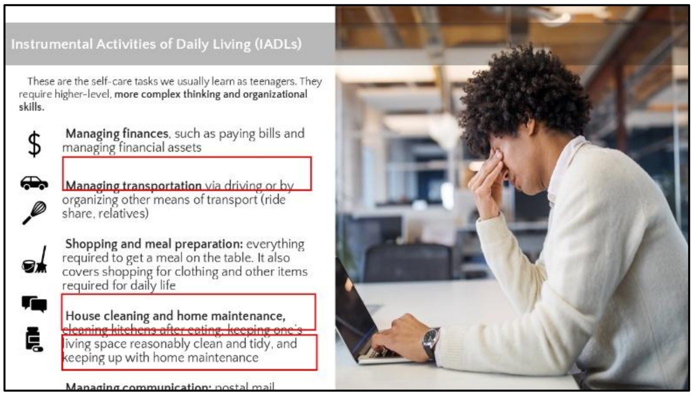
Activities of Daily Living (ADLs)

These are the **basic self-care tasks** that we initially learn as very young children, referred as "Basic Activities of Daily Living" (BADLs)

- **Walking**, or getting around the home or outside. The technical term for this is "ambulating."
- **Feeding,** as in being able to get food from a plate into one's mouth
- **Dressing and grooming**, in selecting clothes, putting them on, adequately managing one's personal appearance
- **Toileting**, which means getting to and from the toilet, using it appropriately, and cleaning oneself
- **Bathing**, which means washing one's face and body in the bath or shower
- **Transferring**, which means being able to move from one body position to another

So, we typically assess something called activities of daily living or ADLs and these are basic, um, life tasks that everyone has to do in order to take care of themselves. So, ADLs include being able to stand up from a seated position, being able to walk from point A to point B, being able to feed yourself, being able to dress yourself, being able to toilet yourself and take a shower. These are considered ADLs, and I think everybody is pretty clear that caregivers are supporting patients in all of these ways.

Reena Cherry:



Instrumental Activities of Daily Living (IADLs)

These are the self-care tasks we usually learn as teenagers. They require higher-level, **more complex thinking and organizational skills.**

- **Managing finances**, such as paying bills and managing financial assets
- **Managing transportation** via driving or by organizing other means of transport (ride share, relatives)
- **Shopping and meal preparation:** everything required to get a meal on the table. It also covers shopping for clothing and other items required for daily life
- **House cleaning and home maintenance,** cleaning kitchens after eating, keeping one's living space reasonably clean and tidy, and keeping up with home maintenance
- **Managing communication:** postal mail

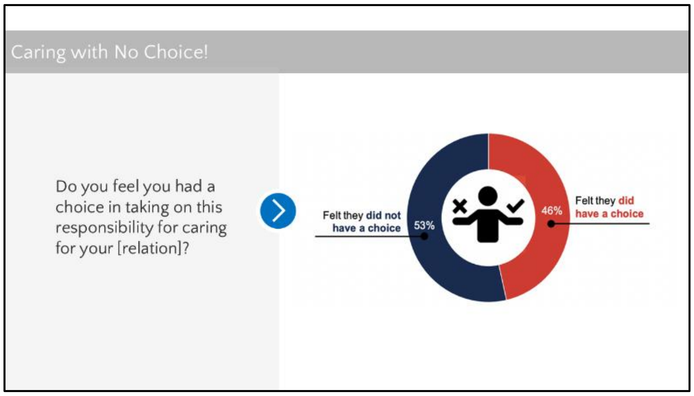
However, there's another category of, um, support, um, called instrumental activities of daily living or IADLs. And I was thrilled to see this category bubble up to the surface because these are a lot of the hidden tasks that caregivers are doing that we are not talking about. So instrumental activities of daily living are more complex tasks. These are tasks that require a lot of follow-up, they require organization and critical thinking skills, and caregivers are in the background juggling all of these.

So, um, I'll quickly go through the list here with you. Certainly, managing finances is a big one. A lot of patients need help paying their bills, rent, mortgage, um, any other financial endeavors they're involved in. When they become acutely ill, the caregiver typically steps up to assist. Transportation is a big one, and I've highlighted that here for you. Patients who require chemotherapy, infusion therapy, are going back and forth to their outpatient clinic to have these procedures done, and the caregiver is either driving the patient there and back or organizing, um, transportation for the patient. So, transportation tends to be huge, and it tends to become more intense depending, depending on what treatment, um, option a patient is moving through. Certainly shopping, meal prep, house cleaning, those are all involved or categorized under instrumental activities of daily living.

Then the last two, I want to touch on communication because this is actually a big deal and I don't hear enough people talking about this caregiving task. So, communication is an enormous responsibility for caregivers, and it has become more enormous over the years. So, 30 or 40 years ago, we had a primary care-based healthcare system, hmmm, where one patient would have one primary care provider and that PCP was managing probably 85 to 90% of that patient's medical issues and every now and then that PCP might have to refer out to a specialist. Well, now the healthcare landscape has evolved into a multidisciplinary platform. So now, one patient very likely has four to five plus active specialists involved in their care. So now the caregiver is not just coordinating care with one PCP, they're coordinating care with every single specialist that patient has. And those specialists have teams of people that help them. So, the caregiver is communicating with a nurse, an advanced practice provider for every single specialist.

In addition, uh, caregivers have the pleasure of also having to negotiate with insurance companies, um, and that is an entirely different talk in and of itself, but insurance has become an enormous burden for everyone, clinicians and caregivers. Um, but caregivers are having to make a lot of phone calls to try to get their loved ones covered for services, et cetera. So, communication is a broad umbrella, but I wanted to just take a moment to really dig into this because it is one of the tasks that caregivers take on that we're really not talking enough about. And then as far as managing medications…, um, patients are on a lot of medications. Many patients were on a lot of medications before they got a bladder cancer diagnosis, and then we add on top of that medications for treatment. Um, patients are also getting medications from specialty pharmacies which require phone calls, et cetera. So, medication management also can be quite, um, burdensome for our caregivers.

Reena Cherry:

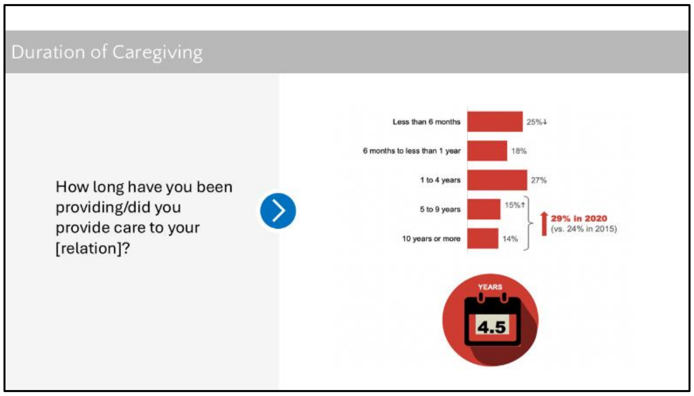


Caring with No Choice!

Do you feel you had a choice in taking on this responsibility for caring for your [relation]?

Um, a couple of other key points from the survey that the National Alliance for Caregiving did, um, is that they identified that at least 53% of the caregivers that they surveyed felt like they had no choice. Which means they, those caregivers felt like they were backed into a corner and there wasn't anybody else who was going to provide support for the patient, so they were it. And the data shows that caregivers who feel like they have no choice, their own health and wellness erodes at a higher rate than caregivers who, um, voluntarily step to the, to the, position of being a caregiver. That's also a critical data point to recognize.

Reena Cherry:



Duration of Caregiving

How long have you been providing/did you provide care to your [relation]?

And then lastly, the duration of care, the duration of caregiving has continued to rise over the years. So as of 2020, almost 29/30% of caregivers reported they were providing support for 5 to 10 years, and that's a large chunk of time. That's a lot of time that caregivers are in this role and supporting, um, our patients. I just wanted to share that data with you as well.

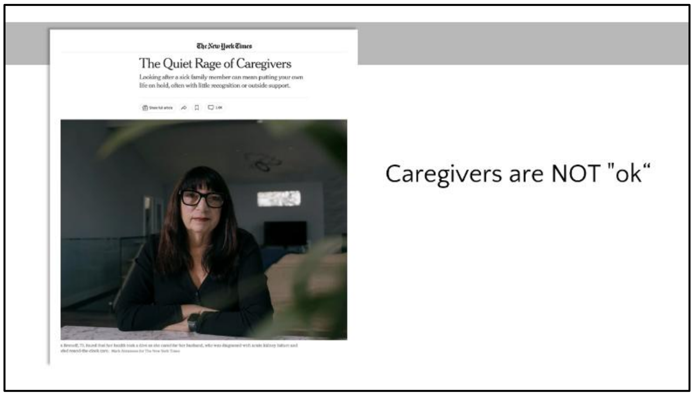
Reena Cherry:


The caregiver code of silence ...

Okay, so I want to talk about this caregiver code of silence. Given all that we have just talked about, given all of the things that caregivers are doing, the question is why aren't they talking about it?

And, um, there are many reasons why, I believe, caregivers remain silent. I'm going to try to highlight those for you, um, and we're going to have to dig into three emotional concepts. The first being, uh, guilt, the second being, um, shame, and the third being vulnerability. But in general, caregivers are reluctant to talk about their journey, and it does have a lot to do with vulnerability, and it does have a lot to do with judgment. And so we're going to kinda try to peel back those layers.

Reena Cherry:


The New York Times

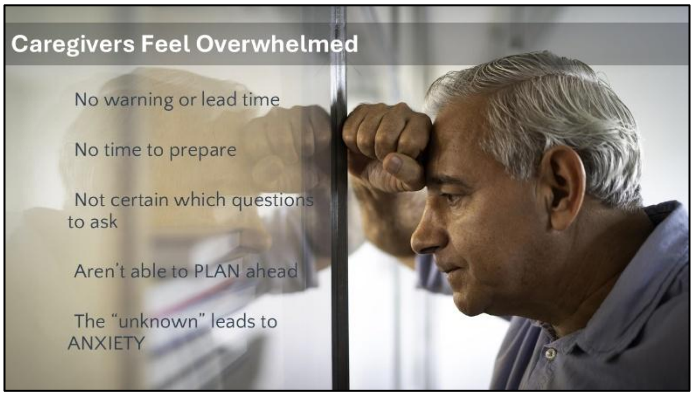
The Quiet Rage of Caregivers

Looking after a sick family member can mean putting your own life on hold, often with little recognition or outside support.

Caregivers are NOT "ok“

So, this was an article that was published in the New York Times, I believe, in 2017, and it's an article that highlights, uh, this woman's caregiving journey of her husband who very acutely went into renal failure, and she very candidly talks about her caregiving journey. And it's one of the first times that I saw a caregiver be courageous enough to talk about her feelings, many of them negative, about her caregiving experience. And so honestly, when I saw this article, that's really what got the wheels turning for me to start digging a little bit deeper into why caregivers remain silent and how we could maybe help them speak out more about what they're going through.

Reena Cherry:



Caregivers Feel Overwhelmed

No warning or lead time

No time to prepare

Not certain which questions to ask

Aren't able to PLAN ahead

The "unknown" leads to ANXIETY

So, um, caregivers, I think, as we all know, are generally overwhelmed. And I think their level of overwhelm, ah, varies obviously, as the patient gets better, their level of overwhelmed dips, as the patient maybe is going through a more intense treatment, their level of overwhelm gets greater. But the reason for their overwhelm is that many times caregivers have no warning you know, their life is going along fine, the next day their loved one has blood in their urine, and then they're on this slippery slope of medical appointments, diagnoses, and treatment. They don't have a lot of time to prepare, um, and I, I want to make it clear that as much as we try to tell patients and caregivers what's coming down the pike, particularly when you have, when you're in that new diagnosis phase, it is emotionally traumatic to hear that your loved one has bladder cancer.

And you sit in those appointments, you hear that your loved one has bladder cancer, and that's like an emotional hit. And then, as clinicians, we move into, "Here's what we're going to do for treatment." And the caregiver, the patient also, but the caregiver does not really have a lot of time to process the diagnosis before they then have to process, "Here's what we're going to do for the patient, here are the side effects, here's what we're going to..." and it's just, it's too much too fast, and I don't have a, uh-uh, I don't have any magic ways of slowing that process down, but I just want everybody to understand that part of the overwhelm is the process of moving through our medical system for better or worse. And then the other issue is that caregivers tend to feel a little less anxious when they're able to plan. But you know the treatment of bladder cancer is a series of procedures and treatments and waiting for scans, and so there's kind this... You're in this sort of space of the constant unknown, um, and when you don't know what's coming, you can't plan, and when you can't plan, you sort of live in this environment of anxiety. So, that's really how, um, the feeling of overwhelm can consume caregivers.

Reena Cherry:

Why do Caregivers Suffer in Silence: GUILT

- They are not the patient
- Discussing their feelings seems selfish
- Idealistic vs realistic expectation

"Guilt is cognitive dissonance where we feel bad for doing something that is not aligned with our values, and we need to make amends or hold ourselves accountable." ~Brene Brown

Um, now I want us to focus on guilt. When I was trying to understand these really deep emotions that caregivers have, I turned to the work of Dr. Brené Brown. Dr. Brené Brown is a doctor of sociology out of the University of Houston, and she has really done some extraordinary work in the areas of guilt, shame, and vulnerability. So, if you are at all interested in learning more about these emotions, I strongly encourage you to read her work. It truly is amazing.

But Dr. Brené Brown defines guilt as cognitive dissonance where we feel bad for doing something that is not aligned with our values, and we need to make amends or hold ourselves accountable. How does this play out for caregivers? Number one, caregivers feel guilty because they're not the patient. They feel very guilty that the person that they love more than anything has this diagnosis and they are healthy, um, so there's a lot of guilt in that. Uh, caregivers feel guilty because you know discussing their feelings in any way seems selfish. We have created a healthcare system where all of the focus is directed towards the patient. And that's not wrong, but it doesn't leave any space for caregivers to express their part of the journey without feeling like they're taking away from the patient, and that leads to guilt.

Lastly, caregivers typically have an idealistic vision of how care should go for their loved one. Most caregivers want the best for their loved one. They want the best hospital, they want the best medical oncologist or surgeon, they want the best treatment, and they want the best home care for their loved one. The realities of caregiving, however, are quite different. And so the difference between what a caregiver can realistically achieve on a daily basis and their ideal vision of what they should be able to achieve, the delta or the difference between those two is where guilt really starts to fester.

Reena Cherry:

Why do Caregivers Suffer in Silence: SHAME

- Feelings are contrary to social norms
- Frustration, anger, resentment
- Experience a sense of unworthiness
- Disconnection leads to ISOLATION

"Shame ... Is there something about me that if other people know it or see it, I won't be worthy of love and connection" ~Brene Brown

All right, now we're going to talk about shame. So Brené Brown defines shame as, "Is there something about me that if someone else sees it or knows it? It will make me unworthy of love and connection." That is shame. And I think if we all think about the times where we have felt shame, this definition is spot on.

How does this present for caregivers? Caregivers feel an extraordinary amount of shame when their feelings about the tasks of caregiving are contrary to what, how they feel about the patient. What does that mean? As a society, we have linked together the relationship the caregiver has with the person they're caring for, their love for that person, and we've linked that with the task of caregiving, and here's how it looks. "If I love my husband or my wife, I love caregiving. If I don't love caregiving or if I resent the tasks of caregiving, I must not love my husband or wife. I must not be a good spouse." And what we absolutely have to do is separate these concepts. It is absolutely possible and is often the reality to love someone unconditionally but resent or strongly dislike the tasks of caregiving. Those two things, are not, they're not, they should not be together. If we can separate these concepts, we create a space between. And the space between is a safe space where caregivers can authentically talk about their caregiving journey without the burden of judgment. And when we create the space without the burden of judgment, we dissolve their shame. And when we dissolve their shame, they will feel safe talking authentically about their caregiving journey. But I want to make it clear that as a community of people in support of caregivers, we have to create the space for them. We cannot expect caregivers to create this space for themselves. We have to start having conversations and open up the conversation so that we detach, we detach the love they have for their husband or wife from their feelings of caregiving. And once we do that, we will start to dissolve their shame.

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