

# "Why is it Difficult to Support Others with Mental Illness? Overcoming a Social Support Quandary"

Charee Thompson

University of Illinois, Urbana-Champaign

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[2022/05/13 11:59] Carolyn Carillon: Hello everyone.

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The transcriptionists are:

LoriVonne Lustre

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The following initials in the transcription record will identify the speakers:

CT: Charee Thompson

[2022/05/13 12:01] Carolyn Carillon: <<transcription begins>>

[2022/05/13 12:01] Carla Heartsong: Hi everyone, so nice to see you!

I'm Carla, from Belgium. I joined Second Life in 2007 and Virtual Ability in 2009.

I used to be a greeter for new people arriving, and a mentor. But gradually I got sick and by the end of 2009 I realised something was very wrong.

In April 2010, I had brain surgery to remove a brain tumour in an important emotional hub of the brain. The presence of this group has been life saving, because unlike doctors, people are willing to listen to more than just medical symptoms, and do not judge.

[2022/05/13 12:02] Carolyn Carillon: CH: I get understanding here

[2022/05/13 12:02] Carla Heartsong: Later on I also had leg cancer and my current disability is a chronic illness, autonomic dysfunction. Brain damage as well as illness affected my mental health.

Therefore I am genuinely proud to present you professor Charee Thompson of the University of Illinois, who will talk about why it is so difficult to support others with mental illnesses.

Professor Thompson teaches and researches interpersonal health communication within families and between medical providers and us, people with chronic illness. Uncertainty, stigma, things like pain and even long covid all affect us.

I would love to point out one of the results of her research, which we know but always think it's just us: our perception of other people's communication about our mental struggles worsen our fear and anxiety. Does it sound familiar?

Professor Thompson will explain the social support quandary and efforts to develop education to overcome it.

As we say in proper English, this topic is right up my alley and probably also many of you, if not just all of us.

Please don't type or speak during the presentation, but she will be happy to answer questions afterwards. And I now proudly give the word to professor Thompson!

[2022/05/13 12:05] Carolyn Carillon: CT: Thanks for sharing your story

[2022/05/13 12:05] ChareeThompson Resident: Charee M. Thompson, PhD, Health Communication

The University of Illinois Urbana-Champaign. Department of Communication

Thank you for being here today and for the opportunity to share some lessons I've learned about supporting someone living with a mental illness.

Slide 2

"It is the social environment and moral condition that is ground zero in global mental health for persons living with mental health illness.

Mental health professionals themselves and family members, moreover, have repeatedly been shown to be the most effective and efficient transmitters of stigma."

Arthur Kleinman (2009). Global mental health: A failure of humanity. *The Lancet*, 374(9690),603-604.

I became interested in studying and improving social support in the context of mental illness in relationships because it puzzled me how people who are supposed to help, and often want to help, could do it so poorly.

Sometimes they don't show up. Sometimes they say and do really hurtful and harmful things.

I wanted to understand why and to help people become better.

[2022/05/13 12:07] Carolyn Carillon: CT: I want to understand how stigma is sustained in close relationships

We don't recognize and change the everyday mundane ways we talk about mental health issues that perpetuate stigma

[2022/05/13 12:08] ChareeThompson Resident: Slide 3 "Our agenda"

I have several goals for this session. First, I want to provide some background information on why supporting others with mental illness is important for health and relationships.

Then, I want to share why support is not very good, even if well-intended.

After that, I will share what I've learned are the difficult experiences of feeling like there is no "good way" to support someone living with a mental illness.

Finally, I want to conclude by sharing some strategies you can enact in your relationship and in your conversations.

Slide 4 "Support is critical."

It seems commonsensical, but a growing literature documents how social support is critical in the context of mental health.

#### Slide 5

In a recent review of research, scholars found that social support was related to higher rates of remission, fewer symptoms, and greater perceived quality of life among those with mental health issues.

Wang, J., Mann, F., Lloyd-Evans, B., Ma, R., & Johnson, S. (2018). Associations between loneliness and perceived social support and outcomes of mental health problems: A systematic review.

BMC Psychiatry, 18(1), 156. <https://doi.org/10.1186/s12888-018-1736-5>

#### Slide 6 “Often, support is...”

absent, poor-quality, even harmful.

People living with mental illness say others’ support failings are stigmatizing at worst and uninformed and ignorant at best.

However, research also tells us that despite its importance and normative expectations that relational partners are supposed to be supportive, social support can be absent, poor-quality, and even harmful.

Sometimes people say things that are uninformed and ignorant at best (think: toxic positivity) and stigmatizing and marginalizing at worst.

[2022/05/13 12:10] Carolyn Carillon: CT: When I say this, I'm thinking about toxic positivity "Look on the bright side ..."

[2022/05/13 12:10] ChareeThompson Resident: Slide 7 “An important question: Why might it be difficult for network members to support people living with mental illnesses?”

I left readings thinking, “Surely people aren’t always intending to be insensitive jerks. What’s going on here?”

I know I’ve often struggled to say or do the right thing.

Thus, a perennial question I have that motivates me is: Why might it be difficult for network members to support people with mental illnesses?

[2022/05/13 12:10] James Heartsong (PeacefulJames Heartsong): fear

[2022/05/13 12:11] ChareeThompson Resident: Slide 8 “What do we know?”

Before I started researching support provision, I did some reading...

Slide 9 “Reasons for not giving support are complex and multi-faceted.”

It’s me: I don’t know how, I’m not very good at it, I don’t see the point, It makes me uncomfortable, I don’t want to seem insincere, I’ve got other priorities;

It’s them: They don’t want support or deserve it, I’d make the person feel worse, They already have support;

It’s our relationship: We’re not very close, It’s just not a part of our relationship, It would violate their privacy;

It’s the situation: No opportunities, No way to get in touch, Don’t live close;

It’s our culture: Helping could be enabling, Women are just sensitive, He needs to man up, I don’t think they have a real or serious mental illness (evidence, inconsistencies).

Dunkel-Schetter, C., & Skokan, L. A. (1990). Determinants of social support provision in personal relationships. *Journal of Social and Personal Relationships*, 7(4), 437–450.

Ray, C. D., Manusov, V., & McLaren, R. M. (2019). "Emotional support won't cure cancer": reasons people give for not providing emotional support. *Western Journal of Communication*, 83(1), 20-38

Slide 10 "OK, but reasons are only part of the equation."

What is the experience of feeling like you should be supportive and then, not giving support or not giving it well?

I'm going to share some answers to that question and equip you with some assistance for your relationship and for you.

Slide 11

I call the larger phenomenon a support quandary.

Slide 12 "An explanation"

In my area of study, it is commonly understood that uncertainty—the unknown, unpredictable, ambiguous—is related to fear and anxiety, which then affects our confidence in our ability to communicate.

[2022/05/13 12:15] Carolyn Carillon: CT: You see a diagram

That shows relationships

[2022/05/13 12:15] ChareeThompson Resident: Not being able to communicate (well) negatively affects communication quantity and quality.

Thompson, C. M., Pulido, M. D., & Caban, S. (2022). Why is it difficult for social network members to support people living with mental illnesses?: Linking mental illness uncertainty to support provision.

*Health communication*, 37(2), 202-213.

Slide 13

To test this idea, we conducted a study of 300 individuals in the US.

These two pie charts show that the majority were Caucasian and had four years of college education.

Slide 14

They reported on friends, family, and romantic partners.

Slide 15 "Results"

Uncertainty predicts decreases in support provision through decreases in support efficacy.

Uncertainty predicts increases in support provision through decreases in fear/anxiety.

[2022/05/13 12:17] Carolyn Carillon: CT: If you trace the green lines, you can see this

[2022/05/13 12:18] ChareeThompson Resident: Positive indirect effect for network, tangible, and informational support through fear and anxiety

- Fear and anxiety motivating for all support types
- Less complicated, more scripted forms of support?

Slide 16 "Results"

Uncertainty predicts decreases in support provision through decreases in support efficacy.

This effect is strengthened when partner gives more and ambiguous info

Slide 17 "Support Quandary"

Uncertainty motivates.

Uncertainty motivates support provision (quantity for all types, but not quality) by activating fear and anxiety.

Uncertainty confuses.

Undermined for forms of support that require complex communication skills (e.g., emotional, esteem, overall quality) through corresponding decreases in efficacy.

So, my hypothesis was largely supported and points to a support quandary—uncertainty motivates us to do something—and people are—giving more support of all types. However, uncertainty confuses and may undermine support that requires more complex skills—so we see quality suffer.

Slide 18 “What is the experience? Collecting the stories”

When we’re in conversation with the person, what are we trying to do? What makes it difficult to do it “just right”?

Slide 19 “Interaction goals”

In any interaction, we’re trying to accomplish three goals: Health, identity, and relationship

Health: I want to attend to your health, get you help, alleviate symptoms, improve well-being/

Identity: I want to appear supportive, compassionate, like a “good” \_\_\_\_; I want you to appear competent, autonomous, feel cared for/

Relationship: I want to develop or maintain this relationship, or de-escalate/terminate the relationship.

[2022/05/13 12:23] Carolyn Carillon: CT: We often have competing goals

[2022/05/13 12:23] ChareeThompson Resident: Slide 20

Want them to be aware they may have a problem, affecting the family, they are different. There is nothing ‘wrong’ with them, all of us have problems/others have been through the same thing.

Getting you to recognize the problem without implying you’re not “normal”.

Steven R. Wilson, Patricia E. Gettings, Elizabeth Dorrance Hall & Rebekah G. Pastor (2015) Dilemmas Families Face in Talking With Returning U.S. Military Service Members About Seeking Professional Help for Mental Health Issues, *Health Communication*, 30:8, 772-783.

Thompson, C. M., Parsloe, S., & Acevedo Callejas, M. (2020). Dilemmas managing doubt about family members’ health complaints: A normative approach. *Journal of Family Communication*, 20(3), 236-249.

Slide 21

Want them to seek outside help, recognize they can’t deal with this on their own.

Boys/men hate this stuff, taught to deal with your own problems, having mental problems is a sign of weakness.

Convincing you to seek help without implying you are weak.

Slide 22

Never give up on them, keep trying, keep talking, always being there for them.

Don’t push and nag, build trust, be patient.

Being persistent but also patient.

Slide 23

Assure them you're concerned and trying to connect, give them a chance to talk, understand what they're feeling.

Validate that I have no idea what they're going through, I can't understand you.

Wanting you to open up without implying I understand.

Slide 24 "Support for the relationship"

Okay, so I've shown numerically and narratively that it can be difficult to provide social support to those with mental illness. Let's talk about how we can support the relationship.

Slide 25

A student of mine did a study of individuals whose partners have mental health conditions. Michelle L. Acevedo Callejas & Charee M. Thompson (2016): Stress, Frequency of Challenges, and Coping for Partners of Individuals with Mental Health Conditions, Health Communication.

She hypothesized that stress prompts us to cope, and coping can affect the relationship.

She found that stress prompts coping of all types; emotion focused coping is not good for relationships; but dyadic coping is good for relationships.

Altogether, stress negatively affects relational quality through decreases in dyadic coping... particularly when the couple experiences increased challenges related to the mental health condition(s), pointing to a need to foster dyadic coping.

To understand how to do this—and to help couples be more resilient and thrive, I turned to some research....

Slide 26 "Stress causes wear and tear"

This is called relational load.

depletion of one's emotional, psychological, and relational resources through repeated, stress-related conversations

Slide 27 "A communication formula"

Research shows that having a communal orientation (we) + relational maintenance = more adaptive responses to stress (resiliency, thriving)

Afifi, T. D., Merrill, A. F., & Davis, S. (2016). The theory of resilience and relational load. *Personal Relationships*, 23(4), 663-683.

Slide 28 "Communal Orientation"

we, together, us, team, our

Thinking of your relationship as a unit when managing stress and approaching life.

Slide 29 "Maintenance Strategies"

Investments in the "bank"

Prosocial, strategic, routine or habituated experiences, behaviors, and actions

Slide 30 "An important question: What can you do right now?"

I could call my family member

[2022/05/13 12:34] Polaris Grayson: be present 😊

[2022/05/13 12:34] Mrs. mama Bmovie (mama Duffield): be compassionate supportive

[2022/05/13 12:34] Sarvana Haalan: Listen when they want to talk

[2022/05/13 12:34] Gentle Heron: "How do YOU feel about this conference's messages?"

[2022/05/13 12:34] RoXkSie (Roxksie Logan): just listen when they need to talk

[2022/05/13 12:34] Lyr Lobo: Share your time and attention

[2022/05/13 12:35] Polaris Grayson: listen

[2022/05/13 12:35] Gentle Heron: My team always tells me to slow down and things will turn out OK.

[2022/05/13 12:35] Shaerken Changeheart (ChangeheartShaerken Resident): /me share an "I notice ....." statement that is both constructive, encouraging, and acknowledging.

[2022/05/13 12:35] Carolyn Carillon: CT: I'd like you to jot down something that you'll commit today

You could do it right now

You can send a message to someone to let them know you value them

I do this in my class

My message is that it only takes a moment

The more it becomes a habit, we can draw on these reserves that we've built up

If you do this now and you'd love to share, I'd love to hear it

[2022/05/13 12:36] Gentle Heron: Asking someone to commit to an action in the very near future is an example.

[2022/05/13 12:36] TheResistor Resident: The sun is shining,

nice and warm,

the air smells of meadow,

a light summer wind blows,

and the birds sing the song:

"Look,

TheResistor" :)

[2022/05/13 12:37] Carolyn Carillon: CT: I love that!

[2022/05/13 12:37] Gentle Heron: ohhhhh sharing a poem is a nice support

[2022/05/13 12:36] ChareeThompson Resident: Slide 31 "Support for the supporter"

Now that I've shared some ways to support the overall relationship, let's talk about some strategies to help boost your support-giving confidence.

Slide 32

Some broad strategies for showing concern

Some specific strategies for providing emotional support

Slide 33 "Some strategies. Not a question of if, but how"

- when to talk
- how to talk
- how to frame the conversation
- where else to turn
- treat yourself positively

We'll go into more detail for the first three, but the latter two are about turning to friends and others for support, advice, validation, pray; and to treat yourself positively.

[2022/05/13 12:38] Carolyn Carillon: CT: we don't talk much about religion but it's an important way to cope

Also looking after yourself

[2022/05/13 12:38] ChareeThompson Resident: You want to help and feel like you have a sense of control in the situation, but the ups and downs do not mean that you are a bad support provider.

Take breaks, resolve that you're doing your best.

We need to show kindness to ourselves

#### Slide 34

When: picking the right time, being available

How: caring, commitment, politeness, respect, listen nonjudgmentally

Framing: positively, cooperatively

#### Slide 35 Let's Practice

Thinking of someone close to you with a mental illness.

Think about your most recent supportive message to be higher in person-centeredness.

[2022/05/13 12:40] Carolyn Carillon: CT: Think about your most recent supportive message to that person

If it helps for later, I'd like you to write it somewhere

So you can retrieve it later

[2022/05/13 12:40] ChareeThompson Resident: Slide 36 "A training program"

[https://rise.articulate.com/share/Cb3mj\\_Ex4zNh\\_6YSUISL0FrQRXOR9vfn#/](https://rise.articulate.com/share/Cb3mj_Ex4zNh_6YSUISL0FrQRXOR9vfn#/)

[2022/05/13 12:41] Carolyn Carillon: CT: It's easy to flip through

I'll give you a couple of minutes to go through that link

Skim it

See what nuggets you can pick up

[2022/05/13 12:41] ChareeThompson Resident: My colleagues and I created this online training module on how to provide emotional support. The training is geared for everyday support providers to those with chronic health conditions, including mental illnesses. [check it out]

[https://rise.articulate.com/share/Cb3mj\\_Ex4zNh\\_6YSUISL0FrQRXOR9vfn](https://rise.articulate.com/share/Cb3mj_Ex4zNh_6YSUISL0FrQRXOR9vfn)

#### Slide 37 "Person-centered messages, a formula for supportive conversations"

Person-centered messages help others feel heard and make sense of their feelings.

In addition, person-centered messages validate the other person, helping them learn that it's okay for them to feel those feelings.

They also encourage reframing.

#### Slide 38 "A communication formula"

Acknowledge + Validate = Reframe

Acknowledge – Label (negative) emotions, connect to them

Validate – Emotions are understandable and justified

Reframe – Help them look forward to a positive future

Afifi, T. D., Merrill, A. F., & Davis, S. (2016). The theory of resilience and relational load.

Personal Relationships, 23(4), 663-683.

#### Slide 39 "Low"

A low person-centered message minimizes, criticizes, or denies the other person's emotions.

Low person-centered messages tell them their feelings are "wrong" or that they are to blame for their situation.

These types of messages often tell the other person how to feel or behave.

"If you'd gotten help when you first started feeling badly, you wouldn't be in this mess now."

"Why are you sad? You have so much to be grateful for."

"You need to get out of the house and stop moping."



#### Slide 40 "Moderate"

Moderate person-centered messages acknowledge the situation but not the feelings of the person in it.

This might mean saying something like, "I'm sorry," or trying to distract them from the situation.

"I'm so sorry to hear you're not feeling great."

"That sounds rough. Let's go get some ice cream and forget it."

"Friends get busy. That's why they aren't spending much time with you. Don't take it personally."

#### Slide 41 "High"

High person-centered messages encourage the person to feel their emotions and provide a safe space to talk through their feelings.

They don't try to "cheer the other person up" or help them forget about the situation.

Instead, they create space for someone to express and explore feelings.

"It sounds like you're a little relieved but also very unsure of the future. I know you are doing your best and I am here to listen and to help in any way I can."

"Why do you think you feel so sad right now? That's completely understandable."

"Tell me more about what you're going through. I'm proud of you for opening up."

#### Slide 42 "Let's practice"

Thinking of someone close to you with a mental illness.

Revise your most recent supportive message to be higher in person-centeredness.

[2022/05/13 12:48] Carolyn Carillon: CT: how would you change it?

I'll give you a second

If I'm being honest, I'm good at seeing emotions but not good at exploring them

[2022/05/13 12:48] ChareeThompson Resident: Slide 43 "Overcoming a support quandary; putting it all together"

Approach it as a "we" issue.

Do everyday relational maintenance.

Provide quality emotional support.

Be kind to yourself.

[2022/05/13 12:49] Carla Heartsong: thank you

[2022/05/13 12:50] Shaerken Changeheart (ChangeheartShaerken Resident): /me whamps paws for Charee!

[2022/05/13 12:50] luluruthy Resident: Thank you!

[2022/05/13 12:51] Hope PAŞŞÎFLØRÅ (LPEaceAndLove Resident): thaank you Charee")

[2022/05/13 12:50] Gentle Heron: Charee, thank you for being so honest about the problems of providing support for our family members and friends with mental illnesses. And especially thank you for giving us concrete suggestions of how we can improve our support.

[2022/05/13 12:50] LV (LoriVonne Lustre): [12:36] EmiAmaris: Do you think it's possible that other people's mental illnesses can trigger our own unresolved issues (trauma, etc.) as well? We may be scared that if we get too involved, we'll lose hold of our own tenuous grasp on well-being.

[2022/05/13 12:50] LV (LoriVonne Lustre): [12:49] luluruthy: I am thinking about how to communicate to others about how they can be more supportive to you. Do you have resources or tips?

[2022/05/13 12:51] LV (LoriVonne Lustre): CT: [How to give people direction on how to support you.. yeah.. for example, if I identify as someone who has depression and I want my Mom to give me better support. I think, going back to our five part model of goals, when I think about giving my Mom feedback on her support, I think she could be better, I have to make sure that I give her those tips, that I tend to be identity goals and also the relational goals, because I like my relationship with my Mom. So I might say 'Mom I really value our relationship, and I love talking and I love that you listen to me, and I feel like a safe space where I can talk about my mental health challenges and I know you are doing your best and you're always so good at making sure you check in with me, I'd really appreciate it if you would do x, y, z'. So notice I sort of walk through attending to the relational thing, then the identity things, and then the ask which is more of the task thing, on how to get better, so affirming the person's identity in the relationship is important]

[2022/05/13 12:51] luluruthy Resident: thanks, yes!

[2022/05/13 12:52] LV (LoriVonne Lustre): CT: Oh yes. Absolutely. there is a dilemma in caring for others that may get in the way of supporting yourself  
Find ways that can be supportive without the triggers. Focus on the triggers yourself  
Then watch a moving with the other to support them

[2022/05/13 12:52] Mook Wheeler: COMMENT: I suspect one of the most common reasons people cannot empathise or support others 'properly' with regard to mental health, is because they cannot imagine the other's situation. The Hercule Poirot character said: 'You attribute always to others the sentiments that you yourself experience.' The inverse is also true: If you don't experience a particular sentiment, you often don't know how or when to attribute it to others. .... Many of the support methods described -- body language, emotional framing, showing, displaying etc -- I am unable to understand or produce 'correctly' in the physical world, and in fact I constantly offend people without meaning to...

[2022/05/13 12:54] LV (LoriVonne Lustre): CT: so much there to unpack Mook

First, I cannot experience what you experience. I cannot be in your body. However, that is not an excuse for not being supportive

When we have uncertainty we have to be careful what we fill that gap with. Cliches can be so dismissive

Absolutely, don't fill the embodiment gap with cliches

In my field we do focus on body language etc... but we know that being present is important

[2022/05/13 12:56] Polaris Grayson: What do you suggest when support fatigue sets in?  
Who supports the supporters?

[2022/05/13 12:56] Gentle Heron: Polaris, we say when you reach out your hand to support someone, you should always also reach your hand back to get support for yourself.

[2022/05/13 12:59] Mook Wheeler: @Polaris -- the family carers have a saying: Look after yourself first, because you cannot serve from an empty vessel

[2022/05/13 12:59] ChareeThompson Resident: Such wisdom, Mook.

[2022/05/13 12:57] Carla Heartsong: thank you so much

[2022/05/13 12:57] Slatan Dryke: great presentation thank you

[2022/05/13 12:57] luluruthy Resident: applause!!! THANK YOU

[2022/05/13 12:57] Eme Capalini: Great job!  
[2022/05/13 12:57] Polaris Grayson: 😊  
[2022/05/13 12:57] Carla Heartsong: 🎉. APPLAUSE APPLAUSE 🎉.  
[2022/05/13 12:57] Eme Capalini: yay  
[2022/05/13 12:57] Elektra Panthar: 🎵🎵🎵 Applauds🎵🎵🎵  
[2022/05/13 12:57] Gentle Heron: Thanks so much Charee  
[2022/05/13 12:57] Sarvana Haalan: Awesome presentation!!  
[2022/05/13 12:57] Tori Herbit Landau (Tori Landau): Applauds, thank you Charee!  
[2022/05/13 12:57] Karlinha Collazo Dufour (karlinha19 Resident): aplauses  
[2022/05/13 12:57] RoXkSie (Roxksie Logan): /me .:{APPLAUSE}..  
[2022/05/13 12:57] LV (LoriVonne Lustre): CT: thank you. Take care