BPD: Caring for the carers

Dr Nicole Hall (00:00:03):

Good evening everybody, and welcome to everyone who has joined us for tonight's webinar and also the viewers who are watching this recording. In the future, I'd like to start with an Acknowledgement of Country. I'd like to acknowledge the custodians of the land, seas, and waterways across Australia, upon which our webinar presenters and participants are located this evening. We wish to pay our respects to elders past, present, and acknowledge the memories, traditions, cultures, and hopes of Aboriginal and Torres Strait Islander people. I'm Nicole Hall. I'm a GP in Southwest Sydney. I do a lot of mental health working in an army and defence area, and I also do a lot of complex women and children's health with people from disadvantaged backgrounds. In the interest of ensuring we have lots of time to interact with our wonderful panellists tonight, I'm not going to go through their bios, it was in the webinar invitation, which you would have all seen. But just to remind you who we have tonight, we have Alex Li, who is a carer of a person with BPD, Julian Browne, an excellent psychologist, and Peter McKenzie, a clinical family therapist, and I'm really excited about the wonderful panel that we have tonight.

(00:01:28):

Before I move into the first question to ask the panellists, I'm just going to give you some instructions about how this platform works. So to interact with the webinar platform and also to access the resources, there are a few options. So you can click the view supporting resources button, which is under the video panel, and that will show you some slides, some extra resources that our panellists have suggested, and the survey, which I would hope that you would complete. At the end of this webinar, there is a live stream chat, which is in the top right hand corner, which looks like a little speech bubble. And if you need technical support at any time, you'll be able to see a tech support button in the top right hand corner of your screen. If your webcast stops at any point, please refresh your browser. This is being recorded, so if you miss anything, you'll be able to have a look at a later time and just some ground rules.

(00:02:36):

Please be respectful of everybody else, participants and panellists, and please keep comments on topic in the chat box. We're not going to have time to answer questions about specific patients, so let's talk about how this is going to work tonight. It's a Q & A session, which I always find really informative and as a really great way of us all being involved and interactive. So I'm going to start with an introduction question for our panellists. Please keep the questions coming through and I'm looking forward to a wonderful discussion tonight. The learning outcomes are on the screen. I'm not going to read them out. You can all read them. And just a reminder, the content in this webinar is for educational purposes only. It is not providing clinical advice, and as I said earlier, we won't be able to comment on specific individual patients. If any content from tonight's webinar courses you to stress, please seek help yourself with your gp, local mental health service or lifeline. Okay, so welcome Alex, Julian, and Peter. I'm going to start tonight's discussion with a question, what does the term BPD mean to you? And Alex, I'm going to get you to start.

Alex Li (00:04:03):

Fantastic, thank you Nicole. And to my fellow panellists and everybody, I should probably start by making a brief disclaimer that first I am as a person with lived experience as being a carer. I can only speak about my own experiences rather than speaking about my person. And also I'm not speaking for only speaking on a personal capacity rather than for any organisations that I work for. But the question of what does BPD mean to me, I see it as a social construct. Obviously there is a set of diagnostic criteria attached to it, and I'm not a doctor, I don't have that qualification, so I can't really speak to that. But having my loved one, having the diagnosis of BPD, it does carry with it certain stigma and consequences when it comes to why the societal implications. And that applies to both being out there in a community societal setting as well as being in a clinical setting as well. That label, that diagnosis does follow you, and as much as I don't like it does carry certain connotation that carry a certain amount of stigma. So to me anyway, I do see it as a social reaction. There's something to be navigated on a societal social level. So that's what that term BPD means to me personally as a lived experience carer.

Dr Nicole Hall (00:05:57):

Thanks, Alex. Julian, I'll get you to go next.

Julian Browne (00:06:01):

Thanks Nicole, and nice to be here and with the fellow panellists and participants. Yeah, look, it's a really interesting question and the truth of it is we don't know the answer to it. I would certainly wholeheartedly agree with everything Alex just said that it is a social construct. And throughout history that social construct has been called many different things. Today it's called BPD. There's certainly a tendency to call it complex PTSD now and so on. Of course, it's a list of symptoms in the DSM four, isn't it? But where does that get us? It's of some use perhaps, but what's of use to me is I suppose how I will answer to this question, and it goes to this question of desire, which is a strange place perhaps to start, but desire, of course, that is what we might think of as wanting is located in the body.

(00:06:51):

We want something moves within us, there's a spark, and we take that into the world. I want x, I want to be a psychologist or whatever, but for someone with BPD, if you ask someone with BPD, what's your relationship to your body? They'll probably say something like, I don't have a body, I'm cut off from the head down, et cetera. So there, there's a cut offness in the relationship to the body. And so wanting tends to be on the other side, wanting is in the other. And we could frame that as the question, what is it that you want of me? Not what I want, but what is it that you want of me? Therefore someone with BPD has their eyes on you, what do you want? Now, I'll add to that, this becomes very difficult because someone with BPD, let's say BPD wants to sustain that desire in the other as an anchor. The experience is one of anchors. So I look for an anchor in you in the other, and to sustain your desire, I must keep that desire alive to keep that anchor holding. And to do that, I must not give you what you want. Now, a hospital might want cured patients, but this is why a hospital is a very dangerous place for someone with BPD because to keep that desire of the hospital alive, I must remain incurable. And this has obviously got huge implications for carers as well and working with carers.

Dr Nicole Hall (00:08:30):

Thank you so much for that. Lots of really interesting points already. Peter, I'll hand over to you.

Peter McKenzie (00:08:41):

Thanks, Nicole. Again, it's lovely to be here and to discuss the whole issues that surrounding this social construct, but I also think there's something about it that's very real as well. And my sense of what is BPD? Well, I agree with both Alex and Julian, and I'm not a great advocate for the labelling, and it's a very antiquated label. I think just to be really upfront with you, I think it should be a part of how we understand trauma, but it still remains an independent thing. And I think Julian was saying that the idea that set of symptoms, well, there is a list of experiences that people have and they're real. And I think it sort of creates a world that appears confusing and I think it's rarely particularly confusing about relationships. And relationships are confusing at the best of times, particularly if they're important relationships to us.

(00:09:44):

And also then the relationship with oneself also is affected I think in this particular group of experiences. But this group of experiences are really a part of the human condition. We all experience them at some point, but we don't experience them all the time. And I think for some people that experiences them a lot and their supporters, this is a really challenging part of life. And so I think that's for me, that challenging you around how we read relationships, how we understand each other is really a part of what, so-called BPD is about for me.

Dr Nicole Hall (00:10:23):

Thanks, Peter. Moving on to our next lot of questions. A lot of questions came through prior to the webinar about carers wanting to know what the treatment is for BPD. And I know that's a broad question, but as a carer, what sort of treatment options are there that can be used to support your loved one with BPD? And how does the carer fit into that? How involved should they be? So Alex, I might get you to start if that's okay. As someone with lived experience, how did you fit into treatment for your loved one with BPD?

Alex Li (00:11:01):

Thanks, Nicole. Treatments, from my own experience, a lot of treatment that involves an overt use of power dynamics, and I'm not going to single out any discipline of mental health workers here, but because power dynamics or the lack thereof can happen just across a number of disciplines. But the one thing that really helped with just about any treatment regime, for the lack of a better word, is that equalisation is for the therapist or the person providing that assistance to be relatable and to be devoid of that power dynamics. So for that reason, other people with that lived experience, or in other words peer workers, they actually were instrumental towards my person's recovery primarily. And that is what I actually hear as well. That power dynamic has been largely mitigated. My person didn't feel as though they're being invalidated or being old to do something. It was a bit like what Peter was mentioning earlier, that the relationship between the person and their carer and also of the wider community is paramount when it comes to considering BPD. So I guess it stands the reason that any attempts to provide support and assistance has to take that community, that relationship into account. So yes, from what I can observe, what really helped is that kind of levelling out of that power dynamic and to that end lift experience work has been invaluable.

Dr Nicole Hall (00:13:08):

Yeah, I think that's a really good perspective to put on things. Sometimes it can be medical team over here, patient over here, carer over here in different corners, and really we all need to work together. So that's a really interesting perspective on things. Thanks, Julian. Psychologist. So you're coming in from another corner

Julian Browne (00:13:30):

Maybe, but in some ways psychologists are some of the worst culprits I think when it comes to providing treatment. Look, there's a couple of different prongs to answering that question because a two-pronged question in a way. So the question first of all about treatment, and I would say that there are many treatments obviously that are effective with BPD, but for me, those treatments need to be on a solid foundation, which involves how the practitioner positions themselves in relation to the client, which is what I think Alex was touching on, that it is let's say a relational, so-called disorder and therefore you must be in relationship to the client and you must be in it up to your neck. And what we know perhaps is that something relational of the client's history will repeat with the clinician and with let's say the team around the client including family members and carers and so on.

(00:14:34):

So we need some experience here to be able to know that that is going to repeat and to accept that as not a failure, but part of the part and parcel of the treatment. On top of that, I would say that a kind of radical acceptance is foundational within the treatment that you're not overly invested on the client getting better because otherwise you're going to end up in a hall of mirrors and that you are there with the client where they are. Now, in terms of involvement of carers, and I do a lot of work particularly with parents of often adult children with BPD, often there is an absolute emphasis on getting the loved one into treatment as a matter of urgency. But until the system around the client is more or less steady and more or less still, which I think is part of the work with the carer, the treatment is likely to be ineffective. That is where we have a very reactive kind of system around the client. All of the treatments in the world aren't really going to have any traction, which of course gives the person with BPDA negative experience of treatment,

Dr Nicole Hall (00:15:49):

Some really excellent points to make there. It can be a complicated dynamic, that's for sure. Peter, I'm really interested in how you feel family therapy fits into this. It can be really hard as a carer to feel like you're sort of on the outside, you don't know what to say, you don't know how you fit into the treatment course. So I really appreciate your thoughts about that.

Peter McKenzie (00:16:16):

Such a good question, Nicole. I'm not sure I've got all the answers to that, but just prior to that, I was thinking about the question and I was thinking, Marshall Anne talked about what's good treatment, what do we need? Well, someone that knows about particular approaches that have a deep understanding of these experiences, also someone that people can connect with. So there's a human kind of connection and that's often unpredictable. I think that's a part of treatment, and I guess that's what you are suggesting is that the sense of how someone that can be inclusive of significant others and people's context, if we acknowledge that the relational element of so-called BPD, this is where things get played out in relationships. And so being mindful and thoughtful, even if you can't directly work with other people, significant others, to be mindful of that context because those people will be in the room with you whether they're there live or not.

(00:17:23):

And so I think the next step is to how do you engage the client to see the benefits of including those significant others? And it is very possible, but it's a process of going back to whether you get that connection with people and they trust you. And as Julian said, it's not a matter of getting to a point where things are fixed, it's a matter of a process of riding through the ups and downs with people and then starting to get that trust. I mean, it does come down to trust in all human conditions and particularly when people are really distressed and disadvantaged. So I think if you can build a trusting relationship with the client, then there's the possibility of including others. And I've worked with particularly mothers and daughters, mothers and sons, that sort of combination. And the way you do that is again, making sure you're really transparent about what you're doing, what's the reasons, having negotiating those processes. So it's a very thoughtful, sensitive process to include others in this work, but it's very possible and the benefits are very significant. I think more so than that, there's a big focus on the individual and somehow if you work on this individual that's having trouble with all their relationships, then how are you going to move forward? But if you include people in a really sensitive way, I think you can get some really good results. So that's my take.

Dr Nicole Hall (00:18:56):

And while you're still going, Peter, I might move on to a question that's come up a lot from people who have registered for this webinar and that's boundary setting.

(00:19:07):

So as a carer, be it for someone with BPD or for many other mental health conditions, a lot of resentment can build up as a carer, why won't they get better? Why can't they just stop doing this? This is impacting my life. It's a fine line between expressing your resentment as a carer, but not wanting to make the person with BPD feel as though they're being abandoned. And it's really important, of course, that the carer's voice is heard. So I'd really like your opinion on how can a carer express how they're feeling without making their loved one with BPD feel as though they're being abandoned or that they're a burden?

Peter McKenzie (00:19:54):

Yeah, another great question, and I get that asked often. I think for me, the first step is for family members and supporters and carers to try and understand the experiences of their loved one, what's actually happening, what's behind this behaviour? It doesn't help the person often the people back away. So what is it that's sort of causing them to react so intensely? I think that's, so understanding is a really important part for carers to start to think about why it's happening. And I think that's one part of it. So I think Julian referred to kind of an acceptance that just to understand what's happening, not to change, just to understand it. The second part I think, is that idea that setting boundaries, I'm not a great advocate for boundaries, the word, it's implying that you can get someone to do something that you don't have any control over.

(00:20:54):

So I'm much more interested, which I think draws from DBTA little bit, the idea of setting relational limits, but their limits that the carer has control of. And so it's not a matter of you should tidy up your room. Well, they might or they might not, but if you need money from me, then let's talk about what that is. And I think starting to establish as almost modelling a kind of sense of these are the limits, these are the things that I can do for you, these are things that I'm able to do that, and there's a really good process for helping people support them to go through that and have those sort of discussions with the person that they're caring for. So I think relational limits are a much better way to frame this. And we've got to get away from this idea that we can control others in a sense. We can only deal with what we are in control of. So that's my take on. So-called boundaries,

Dr Nicole Hall (00:21:52):

And as I often say to my patients, you can only control yourself and how you respond to somebody else. You can't fundamentally control how anybody else acts. And I think that's really important to remember as a carer.

Peter McKenzie (00:22:04):

Yeah, just on that note, it does get complicated when you've got younger people, not necessarily diagnosed, but having some of these experiences. So the idea of responsibility, but yes, just general, I think you're right, Nicole,

Dr Nicole Hall (00:22:20):

Alex, what do you think, what's your thoughts about this as a carer with a loved one? Were there times where you felt like you had to step away?

Alex Li (00:22:35):

Absolutely. And what Peter said about using the term relational limits versus boundaries really resonated with me. And I absolutely have had times when I felt like I needed to step away and before I learned a lot of how to, I'm not going to sit here and say I am the absolute expert at setting boundaries or relational limits. As Peter said, it took me a long time to learn a lot of these, and I still feel like I'm learning a lot of times, but I have had times when I failed to take a step back and failed to, I shouldn't use the word fail, it sounds really harsh, wasn't able to establish those limits. And it absolutely did lead me to a place of strong resentment and it's not a nice place to be, and I can understand how family and carers can get to that point.

(00:23:40):

As for the question of how I was able to walk away or at least be able to do, I thought that one of the most important things that I learned personally was that I had to really emphasise that first, this is just temporary, I will be back. And second it is that I still deeply love the person. So I try my best to communicate those two points, as in say, I can see that things are really difficult for you right now, but this is also really hard for me too. So I'm going that that's first part, I still love you very deeply. Secondly, I will come back in 15, 20 minutes and I will come back and check back on you. So that way I'm communicating A, I still love my person deeply, and B, me taking my step back is for me and for me, and it will only be temporary. So combination of those two things I personally found was very helpful.

Dr Nicole Hall (00:24:53):

Yeah, I think there's some great ideas. Do you mind me asking, did you ever, and I dunno if you know other people who've done this as a peer worker, but did you ever go and speak to a separate counsellor yourself or a separate peer worker yourself just to someone else to sort of debrief with about things?

Alex Li (00:25:11):

I absolutely did, and I did find that getting professional support for myself very, very helpful. And a very large part of it also comes back to repairing the dynamics between myself and my loved one as well. Like what Julian was saying earlier about treatment being a matter of the dynamics between the people involved and that includes families as well. So yes, absolutely. And I have had contacts with lived experience, peer workers as well, not necessarily with the same diagnoses, but people who know what it's like to sit through that discomfort. And yes, so I would absolutely having my time again, I would choose to get my own support every time.

Dr Nicole Hall (00:26:14):

Yeah, I think that's a great message. We're all health professionals in some capacity, but that doesn't mean that we don't also need help with our own mental health. And that can just be debriefing with a colleague or a counsellor. But I think that's really important if you're feeling burnt out as a carer. Julian, lots.

Julian Browne (00:26:35):

Yeah, it's such an interesting question. And of course embedded in the question is an assumption. How can you put in a boundary without someone feeling abandoned? You can't. And the assumption in the question is, oh, I can get the message. And of course there are things, ways in which you send your message, which are important, which Alex was just speaking about, but if you are constantly trying to get your message so the person doesn't feel X, Y, or Z, then that's not a bounded relationship that's trying to get someone to either feel something or not feel something. And so what we're talking about is a separation. So what's the difference between saying how you are speaking to me is unacceptable, versus when you're yelling at me, I can't concentrate and I really want to understand what you're telling me. Now that's a different way of expressing the same thing, which says, I'm here in the relationship with you, but there is a separation.

(00:27:35):

I think often for carers, they're very focused on recovery because that's the answer. And so of course there's a strong push towards getting the person into treatment as we were talking earlier, so that we are extinguishing those behaviours. But of course that's in terms of what Peter was talking about earlier, that's a kind of investment economy where you're investing something so you get a return and the return is the person feeling better, et cetera, et cetera, and getting treatment. But I think where for me, where the work is is in that actual liminal space between us and someone else. It's in fact where the work occurs around that boundary space. It's not what we need to do when things are failing. And if we go back to that question of an anchor, the best anchor you can have in someone else is when they tell you what's okay for them and what isn't okay for them.

(00:28:35):

As difficult as that might be with someone who's desperate and really suffering and drawing us into that suffering, an anchor for that person in that moment might be you stating where you stand in a compassionate way. And I, I often think of the example of a support worker who on her first day with a very severe client with BPD said, now listen, I understand you cut yourself and there's often a lot of blood. I just want to let you know that I don't do blood, I can't do blood, which was a lovely intervention, and that led to a very solid relationship between the client and that support worker where she stated quite clearly where her limit was.

Dr Nicole Hall (00:29:21):

Yeah, I really love that analogy and that example. I think it's, yeah, boundary's not the right word. Thanks for your feedback on that. Some questions coming through, and of course keep questions coming through, guys. There's a question, what if there are family members who are just not interested in being a part of the treatment, a part of being a carer? What if a family member disengages from the person with BPD at all? Are there things you can suggest to? It's a tough question, but I guess what if someone disengages in your family? Julian, I might start with you.

Julian Browne (00:30:06):

Great. I needed some thinking time on that one because I'm a bit confused by the question. Where do you think the question's aimed, Nicole? Is it to try and get the person involved again or

Dr Nicole Hall (00:30:19):

Yeah, I guess, yeah, you could look at it from two ways. How do we get a person who's just disengaged involved again, or conversely, if someone in the family doesn't want to be involved in being part of the process, is it best that we respect that and not have them involved? Is trying to make a family member who doesn't want to be involved just making things worse?

Julian Browne (00:30:44):

Well, in a way, I like the fact that we're now saying family member because I think the word carer, I understand the reason why it's there and that we need to recognise people who are in those carer roles. It's really important, isn't it, because it's a difficult role, but first and foremost, we're a family member, we're a partner, we're a lover, whatever. And we know that with BPD being relational, that there can be something very destructive in relationships and that people often retreat to either protect themselves. When I'm working with a system around a client, I want to hear that voice. I want to hear the voice that is not present because often that voice has something to say. Now I wouldn't have a view that I need to get that person involved so that they are a carer or a support. I think that it's one voice amongst many to listen to because I think everyone around the person with BPD has something to say, which is of value. That would be my response.

Dr Nicole Hall (00:31:51):

Peter, what are your thoughts on this? As someone who does a lot of family therapy, what happens if someone in the family just doesn't want to be involved?

Peter McKenzie (00:32:02):

I absolutely agree with Julian though. Ideally you need to hear the voices that are significant. It's very hard to engage someone with all the complexities and all the challenges they're facing, particularly around relationships without hearing other voices. But at the same time, the reality is that people, I've had families come along and it's usually a kind of TD process where I might see the person that's sort of struggling with these experiences and talk to them about what they need, what they'd like, and I'd talk about the idea of who might be important to be involved and so work with them around this process. It's not a matter of just get the family together and it doesn't work like that at all. And I think if family members are somehow not comfortable, I think my approach to that in a family therapy context would to try and speak to them individually.

(00:33:08):

So I think in a family therapy context, there's a lot of work around subsystems. So working with some people in the family, working with individuals, working in a sense, trying to find the best sort of combinations for what people are expecting. But I think I have to respect also in a live situation where there's a lot of energy, there's a lot of conflict that sometimes it is important that people take care of themselves. And if it's a bit too much then, but I would follow that up and I would keep that conversation going in one way or another. They might return, they might not, but as Julian said, but we need to keep hearing those voices. And there's, in family therapy, there's a thing called circular questioning where you can ask people about What do you think? John's not here, he didn't want to come today. What do you think John would be thinking? So asking other people about what their thoughts are, and it's a very effective way to bring that voice in of, and even the person that's struggling with these experiences to get them to reflect on, what do you think, John? He didn't want to come, but what do you think he'd say about that? And I find that a really helpful, engaging process even when people are not sitting in the room. So that would be my take on it. Yeah,

Dr Nicole Hall (00:34:28):

I really like that concept of what do you think John's feeling? If John's not here, you're still bringing them into it, even if they're not in the room. Alex, as someone with lived experience, I don't want to make it too personal for you, but were there people involved in your life that perhaps your relationship struggled with because they perhaps pulled back from the person with BPD?

Alex Li (00:34:58):

I guess I will answer that question starting off by asking another question, which is, and I'm not looking for an answer, it's more like a rhetorical question. That is your question of what, how can we get the family back engaging? Is that, I wonder if that question came from the person with the living experience of BPD or is it from another family carer, or is it actually from the therapist or whatever professional was being involved without spending 10 minutes trying to unpack those three groups. But I feel that if the family and carer, they are not for whatever reason wishing to engage, it almost feels like bringing that boundary question or relational limit question that talking about earlier. And each party in that dynamic, it feels like they have to answer the question themselves. Am I willing or does my value allow me to proceed despite that person not willing to engage?

(00:36:16):

Because as you have seen, it's not possible to drag someone to do something. It's Julian and Peter, you both alluded to, if someone isn't going to do something, it's not within our control to make them do it. And I think that applies equally to other family members as it does to the person. Then the question becomes, yes, it's nice to get everybody involved in the process, but to what extent is that, what cost is that going to impose upon? If I'm going to sit here and speak as a family member, I have to consider to what extent is that going to impinge upon my value and consider whether or not that's an acceptable price to pay for that person to be that particular family member, to not be involved in a process as much as I want to. I can't drag them there. And that's a question that each person will have to answer individually, I think.

Dr Nicole Hall (00:37:27):

And I actually really like that you brought up values there. I think it's really important as a carer for someone with BPD or other mental health conditions, just as it's important as a health professional to know what your values are because they're really important in determining how you interact with family members and patients as well. Next question, this has actually come up a few times. So any tips for carers of people with undiagnosed BPD or people who are not accepting of their diagnosis of BPD and therefore who are unwilling to engage in care and in treatment? Tough question. Who will I pick to go first? Peter, you've had a break.

Peter McKenzie (00:38:18):

Thanks, Nicole. No, actually it's a really good question. It's something that I have quite a bit of experience with. So a lot of families that come to see me both, I run workshops as well for families, not including the person himself, but with the families. There's a considerable amount of people that come that they don't have, there's not a formal diagnosis around. And one thing that I do talk to the person that maybe was contacting me about possible having a meeting or having a discussion, was that the terminology, the diagnostic kind of criteria, I don't think it's essential to have discuss. Often family members said, I've been on the net and I'm sure it's borderline pd. That's definitely the case. And I guess I encourage them to see it as an sense, as a set of more of a framework around maybe complex trauma or complex PTSD.

(00:39:18):

So I try to introduce that concept, but then I'd relate it to, well, there's a bit of a discussion in psychiatry about that, but not labelling it I think would be an important part of it. So the people experiencing a number of related experiences. So therefore, yes, that could be the case, but we can work with those experiences. We don't have to label them as such. So that would be sort of my first point of call, that it's not necessarily, I don't think, well, my working conditions in my private practise and also where I work at the brew centre, I don't need a diagnosis to see people. And I think it's sometimes important to acknowledge that the diagnosis is just a label, and it can be helpful for some people. Some people find it a relief, other people find it very stigmatising. So there's a whole lot of range of responses, but I don't really think that it's necessary to have that and we can work with those group of experiences quite clearly. I wish only that we could rewrite those nine criteria and some reasonably humanistic language would be nice, which I often do with people, families, and say, well, what you call this? What's your name for this? And so we come up with some really interesting and really helpful ways of talking about this, and that's a really important strategy for me to do that. So maybe that's a long-winded answer, but that's sort of what I got.

Dr Nicole Hall (00:40:48):

That's great. Thank you. And I guess speaking of diagnosis, coming from a doctor perspective, there's so much emphasis on do they meet the diagnostic criteria for this? Do they meet DSM four or five criteria for this? We have to fill in paperwork. Do they meet criteria? Do they meet criteria? So it can be hard sometimes, can't it? There's a list of criteria, but that's not necessarily applicable to what's actually happening in reality. Julian, what are your thoughts on this? How do we engage someone that maybe doesn't, doesn't necessarily want to accept that BPD is something in their life?

Julian Browne (00:41:28):

Well, what was Peter saying? It reminded me of John Gunderson, who's no longer with us, of course, but McLean Hospital in the US, he wasn't, I mean, the diagnosis is important, obviously, and for some people it's a revelation and important, but I don't really care if someone has the diagnosis or not. I think that fundamentally we're all a little bit BPD sometimes, sometimes all the time. And so what does BPD teach us? It teaches us about what it means to be human, and it teaches us about how to be in relationship with others. So what tends to work that we've been referring to tonight is a set of principles. Now, those set of principles which are acceptance, curiosity, understanding, sense of separation between I and thou, et cetera, et cetera. Yeah, those are fundamental principles that work with your loved one, with a friend, with a family member.

(00:42:36):

It's irrespective of whether someone's got a diagnosis or not. So I apply those principles in all of my work regardless of whether someone has a diagnosis or not. And as Peter was saying, which does remind me of John Gunderson, he used to run a psychoeducation session. Now, normally that would involve the psychiatrist telling the people with BPD what BPD is? No, no. He says, what is BPD to you? And sometimes when I'm pressed for a diagnosis from a client, they ask me what their diagnosis is, I just give them their name because each person there are as many bpds as are people with a diagnosis. So I don't think the diagnosis is critical at all because it's founded in a set of principles.

Dr Nicole Hall (00:43:29):

Yeah, that's a really great answer to that question. It's just a shame that sometimes from a Medicare funding point of view, we have to make a diagnosis per se. Alex, this is an interesting question that's come through. How does the person you care for or your loved one feel about you being on this panel?

Alex Li (00:43:51):

She's fully aware, full disclosure, and as I said at the beginning, as carer lived experience, one of the things that I subscribe to is that I'm not speaking for my person. Sure. The title of this talk tonight is about BPD, so we have to talk about that. But if this webinar were to be about mental health in general or how to be a carer, et cetera, regardless, diagnoses, I wouldn't even have talked about diagnoses as for the question of how would they have felt about it because, and that is something that we have, we have navigated together. We have spoken in other contexts separately and together, but we also are in consistent dialogue about what kind of things that we are comfortable talking about with regards to each other. I mean, she's spoken in other context about me as a carer, but we both know where we can, what kind of things we feel comfortable with the other person talking about. So I think it comes down to what was discussed earlier, what Peter was saying earlier about treatment being a trusting relationship. It's all about trust. And I feel that our relationship between family members is definitely about trust. And it also goes to me knowing that I am purely speaking about my own care experience, and of course I have to deliver on that on a consistent basis to earn that trust as well. So that's my long-winded way of saying, yep, I'm just here to talk about myself, therefore, and hopefully I can stay on track.

Dr Nicole Hall (00:46:05):

Thanks, Alex. One of the questions has come through. I'm going to reword using an example from my practise. So I have a family that there's some complex relationships, and the mother came in to see me a few weeks ago and says, my child who is 17, has all of these issues. She obviously has BBPD. And the next day the daughter came in and said, my mother has all of these issues. She obviously has BPD. So Julian, obviously we only get told bits and pieces. How do you break that down when there's multiple people in a family accusing the other of possibly having BPD traits?

Julian Browne (00:46:54):

Yeah, look, I haven't had that situation, or maybe I have, but without seeing both family members, yeah, look what is a diagnosis, because as we know, it's very popular in society to diagnose loved ones and friends and so on. And there's the latest trend in diagnosis. I think narcissism is the latest. Yeah, okay, so what is that tendency? And of course, perhaps it's something which is experienced as too much in a relationship, which we then go looking for answers because we're anxious. And if we've got an object to locate our anxiety, then that helps us to moderate our anxiety and therefore we start to label people, et cetera, et cetera. So for me, those moments are beginnings, the beginnings of an opening where there might be a discussion about what's actually going on in the family and just as a diagnosis is an opening. It's not the diagnosis, it's the person's relationship to the diagnosis. For me, I would just roll with that. I'd be very interested to hear both people's experience of what's occurring in the family to begin to open a question that might be fruitful or cultivate something of an opening within that family, which at the moment, clearly the experience is of something being too much relational.

Dr Nicole Hall (00:48:31):

Yeah, that's a great way of looking at it. Peter, I'm interested to hear your thoughts.

Peter McKenzie (00:48:36):

Well, I think Julian just stole all my thunder. Really, really, that's almost word for word how I see it. This is an opportunity for family members to come and have a bit of a chat about what's happening and how the relationship's going. And all these labels, we label each other all the time. You are angry, you are upset, you are uncooperative, or you've got BPD. For me, I blame Google. Really, it's just too accessible. Wikipedia, I'm sorted. So I think it is about looking at the relationship and yeah, you can take note of these things of course, but really looking at the relationship and do people want to have a discussion? Do they want to have a dialogue about their relationship? And maybe I can facilitate that for you and be active in that discussion with you, but that's exactly how I see it at the same as Julian. Yeah.

Dr Nicole Hall (00:49:44):

Let's talk a bit about multidisciplinary teams. So that's one of our learning outcomes. Julian, I might start with you. Do you see that there's a role for MDTs in the setting of BPD? Do you engage other health professionals when you're managing someone with BPD?

Julian Browne (00:50:06):

Yeah, look, my work often involves large teams and so on. When I'm providing direct treatment in my private practise for someone with BPD, I am liaising, which is really critical. Now, what's the reason for that? The person with BD, because of what I was saying earlier with respect to desire being located in others, then what BPD does is respond to different contexts in radically different ways. So the way someone behaves in an emergency department might be different from at home, might be different from their psychologist, et cetera, et cetera. And so you have a multi there already in all of these different contexts. And we had a saying at spectrum, you treat the system before you treat the client because unless, because of course all those different realities often are conflicting with each other and often are judging each other, that's where you have fragmentation within a system and splits and so on and so on.

(00:51:16):

So the first thing you do in a sense is pick up the phone and ask in the same way as you might with a client, what's going on for you? What's your experience with the client, et cetera, et cetera. Now, I'm a huge fan of multidisciplinary teams because as I said earlier, sometimes those who are meant to know psychologists, psychiatrists, and so on are the worst culprits in terms of needing to be a master over the treatment, knowing what the client needs, et cetera, et cetera. And so when there's a multi in terms of a discipline, then you are often hearing different multi perspectives. And that's what for me, the foundation of the treatment is multi perspectives rather than one right perspective and the other perspectives are wrong. So that's how I would respond to that question. It's absolutely critical.

Dr Nicole Hall (00:52:13):

Thank you for that. Look, a really interesting question's come through. Someone has said, I wasn't aware that someone with BPD needed a carer. Alex, what do you think? It's an interesting question. It's an interesting point.

Alex Li (00:52:30):

Absolutely, it is. I guess it depends on what that question, how they define "carer" because coming back to what Julian was saying earlier, we are not carers, we are family members, we are mothers, fathers, sons, daughters, et cetera. And my person doesn't like the term "carer" either. Once again, like Julian, we both understand from a policy perspective, from a documentation perspective, that's the term that's being used. But we certainly acknowledge the, and we certainly understand the limitations and certain connotations that word carries. And I know a number of people who have been in the carer lived experience world for a lot longer than I have who openly say that they don't like the term carer. I guess it does carry a certain connotation of that power dynamic that I was talking about earlier, because to have a carer means that you've got to have a "caree".

(00:53:49):

So there is something that the carer is doing true, it feels like it's something the carer does for or does true the "caree", which doesn't always sit well with me personally, but if we reconsider the term carer into what Julian was saying as a family or whatever way you choose to define family, but it is a matter of relationships. It is a matter of recovering in a set of relationship like Peter has mentioned a couple of times. So if you look at carer in the word carer in terms of dynamics, then in that case, I think we all need carers, every single one of us on Earth PD or not. But if you look at it from a very narrow, oh yeah, I care for you, you must receive care from me, then perhaps that question is, that question is valid. It really depends on how one looks at the word carer, and I think it should be a question that we should all encourage each other to think about.

Dr Nicole Hall (00:55:05):

That's a really great answer. Thank you. A question I really like, which I think we're going to spend a bit of time on, and we've touched on this a little bit with you, Alex earlier, but what are some practical strategies for family members in a caring role to take care of themselves? Peter, I might get your thoughts on this.

Peter McKenzie (00:55:28):

Yeah, it's a good question. I don't think there's even a simple set of answers. It depends on the context of people and there are limitations they have around work and relationships and the like. It also depends a bit on the perception of the services that are involved and how the kind of support that they might be receiving from them as well. So just going back to the previous question about the idea that your multidisciplinary teams, the idea of care coordination is such an incredibly important part of this work that services need to be on board and have some dialogue about it. If you don't get that, then it really doesn't sort of move very fast. So just in that sort of vein, and I think getting support from not just each other but the different services or multidisciplinary teams involved to recognise the role of the family member or supporter is really important because sometimes we don't know what we need in a sense.

(00:56:35):

So it's often having discussions about how you're coping, what's happening for you, what have you tried, what do you think it might work for you. It's more like having that question asked in the first place, how are you doing? How's things going? It sounds like it's been pretty tough for me, the key. And from that, there'll be things that happen, but you want services and therapists to ask that question to acknowledge that. Otherwise I worry. Sometimes people want some advice about what can I do? And they go and try and it doesn't work. And it's very disheartening when a professional suggested something and it doesn't work. So I'm very, very sort of sensitive about let's explore what's been working for you, let's explore, and the real frail things that don't seem that significant can be significant if people can have a chat about it. So it's in narrative therapy, they call it the thinly known kind of activities that people don't really pay much attention, but well, maybe now that I've talked about it, maybe I will keep, that's sort of working a little bit, but it's not what I would hoped. So that kind of conversation I think is the most important pre-conversation before we give advice about what might work, go for a walk or something like that. So yeah, for me, that's the most important. Ask that question. How are things going? It sounds like it's been really tough. How are you coping? How do you cope? That's a great question. How do you cope?

Dr Nicole Hall (00:58:16):

Yep. Okay. And asking that sort of question can really open the door, can't it? To a whole other conversation when working with BPD and Neurodivergence and other comorbid other mental health conditions, but particularly Neurodivergence. This question is about are there any particular interventions that are more beneficial? Julie and I might get you to comment on that.

Julian Browne (00:58:42):

I thought you were going to ask me that. Sorry about the mood lighting. By the way, the light club just literally blew in my room. Yeah, look, I feel like I'm answering every question in a sense with a question in a way. But look, I know that neurodivergence is our reality at the moment, and there's an acknowledgement of neurodivergence, which is very important. But my view is that we're all neurodivergent in one way or another, which is not to minimise the experience of people who are really suffering in a society which values a norm, which is supposedly not divergent. Okay, so I'm going to come back to the principles again, and I do a lot of work with teams who are working with someone with a diagnosis of BPD and autism or ADHD or a range of other diagnoses, intellectual disability and so on.

(00:59:42):

First and foremost, to come back to what Peter said earlier is understanding that we need to understand what it is that the client is contending with, but also first and foremost, what tends to happen when there's a so-called disability is that that becomes the ranked number one mode of treatment, which I think is a huge issue with NDIS at the moment. Because if you're working in a disability model and the individual has BPD, you are going to be very counterproductive almost every time. So each time your interventions need to be on the foundation of that set of principles, which are counterintuitive when you're working with disability. So for me, number one, BPD number two is then we consider all the other factors, which might include processing issues, verbal expression and understanding and so on. That might complicate the picture, but it's always on that foundation of BPD principles.

Dr Nicole Hall (01:00:58):

Thank you for that. I feel like we're running out of time. There's so many great questions. I do want to touch a little bit on support groups. Now, I know that we're all in different places all over Australia, but I'm going to open this up to all three of you. Are there good online resources that you know of? Are there specific groups that you can recommend? Are they good? Someone specifically asked about support groups in Sydney, but what resources do you like that we can suggest to people? Alex, I'm going to put you in the spotlight first. Did you find that you think in particular that was good from a support point of view, a good educational resource?

Alex Li (01:01:41):

Yes, there would've been a few. There would've been a few that helped me along the way. The first thing that I can think of is the Family Connections programme, which is run by NEABPD Australia. So that's National Education Alliance of BPD Australia, and it's a 12 week programme. It doesn't require your person to have a diagnosis, even though it's run by NEABPD. You don't need a diagnosis to join that for the family and carer to join that programme. Long story short goes for 12 weeks, two hours per week. And I personally found that one of the first things that really taught me, I went into the course thinking, I am doing this to deal with my person or to mitigate whatever their behavioural manifestations are. Say for example, if they feel super elevated, I know how to deal with it. As it turned out, I actually learned how to deal with myself, especially when we started talking about things like how to set that boundary, how to clarify my own values and being able to communicate that, what I said earlier about expressing that, telling them that I have to take myself out of the situation, but I'll come back to you basically learn that from there as well.

(01:03:29):

Yeah, so given the limited time, that would be the first one. That would be the first one that I would mention. Yeah.

Dr Nicole Hall (01:03:39):

Wonderful. Thanks Peter.

Peter McKenzie (01:03:43):

Yes, I'd just like to endorse Alex talking about family connections, which is probably nationwide now. And the only challenge is that you go on a bit of a wait list until there's enough people to form in your area. So it's not often an immediate response. So that's, just be careful of that. As far as groups go, there's hardly anything really. And group work is really challenging for this group of people, for families in this context. And I know there was some in Victoria anyway, there was another group as well, and I know Spectrum run a sort of family information sort of half day as well. So there's sort of bits and pieces here and there, but the spectrum one particularly is really good. I also run, and I used to run this two or three times a year, but it's a lot of work. So I run a two day workshop for family members as well, running a little bit similar along using a whole lot of ideas from DBT dialect, behaviour therapy, and a range of other things.

(01:04:54):

So that's one half of it, but the other half is actually a therapeutic kind of group. So I guess sort of referring to Alex that carers need, I think they need a bit of support around reflecting on their own, what the impact this has and what it means to them and their relationships and how they are in relationships. So that particular, it was a two day thing, so we can afford to have a bit more time. And I use what is called an outsider witnessing process, which comes from narrative therapy where it's a bit more structured, but basically interviewing someone about their story and then engaging people with their reflections around that. And I find that really, really important to have a bit of a therapeutic response to carers, not just simply support and education, but actually address or try to acknowledge some of their own sort of deep seated challenges that they face. So that would be the group that I run, and that's part of the Bouverie centre. Everybody wants to just check out our website, but otherwise, not a lot. And carers are really, carers families are really the missing link in all this stuff because it's complicated. There is, I know there's some therapists that, and particularly a colleague of mine, a colleague of Julian's that also works with families as well around borderline PD. So there's a few people around, but yeah, it's not widespread.

Dr Nicole Hall (01:06:24):

Thank you for that. Some really great suggestions there. So that was the Ruby Centre in case anyone missed it. Julian, any thoughts?

Julian Browne (01:06:33):

Yeah, look, I would just echo what Alex and Peter was saying. It was interesting, wasn't it? What Alex said about, well, where we might start with as a carer would be, what can I do to help my loved one? And where he arrives at is how can I manage myself? So this is the important thing. And so for me, obviously resources are important and I would echo everything that people have mentioned. And there's also the BPD foundation as well, obviously, but there is scant around, and for me the ultimate resource is the carer. And so I am strongly encouraging wherever possible, and I know this is obviously a shift in mental health services around Australia, but that we bring in family to learn something and so there's a dialogue that's occurring with the family where possible. Now of course, sometimes a client doesn't want that to occur, but the family is the resource in a sense. If we're listening, the family is the resource. And so we are it in a way. There's often not somewhere we can send someone to get support that where is, and if we have a more inclusive model around treatment, I think that would be a good,

Dr Nicole Hall (01:08:12):

Yeah, great thoughts. Unfortunately, we are coming towards the end of our webinar, there's some excellent questions. I apologise we haven't been able to answer. I'm going to get each of you if you can, to just give me a little summary. What's your two minute reflection on collaborating in this area? What's your final message? Peter, you're on my screen so you get to go first.

Peter McKenzie (01:08:40):

Well, I think we've been pretty clear about that, isn't it a sense? And the fact that you've got the three of us on and coming from slightly different perspectives, but in a sense, I don't think I've ever been on a panel like this. It's been so connected as far as our thinking, so it kind of validates me, which is great. But I think it's thinking about this relationally is the key. We've got a system that really pushes us towards the individual. And I know it's bureaucratically kind of okay, it works, but to how to think relationally, even when we are not actually seeing the context of relationships or other people, we might be seeing an individual, but to think relationally around this is really important and to collaborate with others because there'll always be other people involved. If people are having this group of experiences, inevitably there'll be other services engaged and other people and to be really collaborative around that. So think relationally and be collaborative is my two sort of points.

Dr Nicole Hall (01:09:46):

Wonderful. Julian?

Julian Browne (01:09:48):

Yeah, they're nice. So I just want to add to that, and I suppose I would want to emphasise here in the work that I do with systems and also in my clinic, that we tend to kind of impose a recovery oriented model onto BPD. And there is no research. It's intuitive. We think, oh, well of course recovery oriented model is a great improvement over the bad old days of psychiatry, which is true. But a recovery oriented model is outcome oriented. And to go back to what Alex said earlier, if the carer or if as a clinician we are pushing towards an outcome with a client with BPD who is absolutely split down the middle with respect to I want something for myself and yet I have to refuse that thing at the same time, that's the split. Then with a recovery oriented model, you're in trouble. So it's contraindicated. The normal standard approach to treatment does not work with BPD. So it's paradoxical and it's because of what I was saying earlier in terms of the nature of desire. So where do we position ourselves? We position ourselves as in our work and wanting to do our work with the client than wanting them to have a good outcome. I know that sounds paradoxical, but it's mirroring what Alex was saying earlier, that we have to manage ourselves. The business of working with carers or with BPD is the business of managing ourselves.

Dr Nicole Hall (01:11:33):

Alex, digress to you for your final comment.

Alex Li (01:11:37):

Lovely, thank you. I feel like one of the threads that has been travelling throughout tonight's conversation is that BPD as a diagnosis is really difficult, can be very difficult to pin down. Like what Julian was saying before about it being, it comes down to certain principles and what Peter said about the labelling of people having those experiences as these days as a family carer lived experience worker, I do believe that people are the authors of their own recovery and which goes to what Joanne was saying, that if they have that particular desire, if they, if they interpret their distress in a particular way, then working with that rather than against that is probably the probably best way to approach that, especially since in the lived experience world, we believe that there are different ways, different frames where emotional distress can be looked at. So I guess I just want to acknowledge that threat that has been going through the conversation that yes, from a Medicare point of view, the label diagnostic label is important, but it's also important to consider that.

(01:13:11):

So-called treatment or how we support our people comes down to what works ultimately for the person. And that also applies to the carers through the family and carers as well. And also for, this is going to sound like a bit of a cord to action, but I do believe that there is room in the system to recognise that family and carers have their own recovery journey. Not to say that they all need to go and see psychologists, psychiatrists, et cetera. That's not what I mean, but family, and there is research backing that up too to say that family and carers experienced their own recovery journey, finding their own, and the key is finding their own connection and hope, et cetera. So like what has been mentioned several times tonight, recognition of that journey will help the whole, I believe will help the whole family system, the people involved together in the person's recovery.

Dr Nicole Hall (01:14:12):

That's a wonderful comment. I much appreciate that. And I guess I'd just like to add that everyone on this webinar is a carer for patients, for clients, and we all need to look after each other as well and collaborate with each other and support each other. Thank you to everyone for participating in tonight's webinar. It's been amazing. Thank you to our wonderful panellists. Your insights have been very enlightening. I've learned a huge amount in a short period of time. There's a slide on your screen about some excellent webinars and podcasts from MHPN. MHPN supports more than 300 networks where mental health practitioners meet both online and in person, and there's some excellent networking opportunities. So I really, really encourage you, if you're interested in finding out more, to visit MH PNS website and to have a look at their other webinars and have a listen to some of the podcasts.

(01:15:08):

I will please ask everyone to complete the exit survey and provide feedback because that's really useful for us to make our webinars as good as we can for everyone moving forward. Statements of attendance from this webinar will be available on the MHPN portal in about two weeks time. And this webinar recording and a link to the resources that have been mentioned will also be available on that portal in about a week. And before I close, I'd like to acknowledge the lived experience of people and carers who have lived with mental illness in the past and those who continue to live with mental illness. Thank you everyone for your participation this evening and goodnight.