

## **SUMMER FOUNDATION BREAKFAST CLUB LECTURE ONE 2017:**

### **KATE GOULD & AMELIA HICKS**

Okay, hello everyone. My name's Margaret.

Welcome to the first of our Summer Foundation breakfasts for this year. It's lovely to see so many happy faces in the audience for a nice, early morning start.

It's my very great pleasure to introduce our speakers today, so we have Dr. Kate Gould and Amelia Hicks.

They're both research fellows at the Monash Epworth Rehab Research Centre, which is a bit of a mouthful, and they're going to be talking about a particular project that they're involved in called the behaviours that concern following traumatic injury project.

Just a little bit more about their backgrounds, Kate is a clinical neuropsychologist in private practice, and she has just actually started her own private practice now. Many of you might know her through her association with Sloane Osborne & Associates, but Kate has just started a new practice called Thinkfully, and Amelia, has a Masters of Psychology in clinical psychology as well.

So it's going to be a fantastic talk today, there are a few different things happening.

First of all, there'll be about a twenty minute discussion from Amelia, introduction to the qualitative aspects of the study.

Then Kate is going to spend another twenty minutes talking about that, so you get a bit of a difference from them, and then at the end of that, we'll open it up to some general discussion. If you have any questions, Amelia and Kate are very happy for you to just interject and ask away, but any philosophical questions and so forth, perhaps keep them for some really good discussion at the end. There are no other particular announcements, but for those of you who might need the bathroom, and are not familiar with this place, you need to go back out that way and round to the right, and I think that's it. Anything else that we need to cover? All right, terrific, thank you very much.

(Applause):

#### **Kate Gould:**

Okay, thank you for that lovely introduction.

So today, I'll be discussing our study which examined behaviours of concern following traumatic brain injury.

So what are behaviours of concern or challenging behaviours?

So they cover quite a wide spectrum, from violent, aggressive behaviour, shouting, yelling, physical violence, self-harm, all the way to apathy, or lack of initiation, but also include things like perseverative behaviour or repetitive behaviour, wandering or absconding from safe places into more risky areas, and also, inappropriate sexual behaviour and social disinhibition, so that covers a really wide range of things including being a bit socially awkward, being inconsiderate, interrupting, nagging, impatient. And what we know from the

current research base is that these sorts of behaviours are quite common following moderate to severe brain injury, and they're not restricted to the acute period after brain injury.

They continue on into the more chronic period, and for some people, they can worsen over time.

The causes of these behaviours are really complex, and I've just grouped them into three general areas for today's talk. So we can think about them in terms of the pre-injury, personal and environmental factors, so perhaps a person who was already having problems with their behaviour.

They might've had problems with alcohol or drugs or a psychiatric diagnosis, then there are the actual injury-related factors, so they may have sustained multiple systemic injuries and be in a lot of pain, be really uncomfortable and frustrated, cognitive difficulties, reduced judgment, insight, ability to self-regulate, and also, reduced communication or being completely nonverbal and the frustration that that causes when needing to communicate just those basic needs.

Also, a whole host of post-injury factors, so mood changes, we know that anxiety, depression, PTSD are all quite common as well, limited ability to return to valued life roles, so whether that was being Mum or Dad or being a student, their work role, and also, the changed financial situation that happens as a consequence of that.

Just talking a bit more about consequences, they're really broad and far-reaching and they affect not just the individual, but also their family, friends, carers and the health-care system at large. So just some examples up there on the slides. For the individual, reduced capacity to live independently, relationship breakdown, dislocation from accommodation. For family members, a lot of stress, research shows lower quality of life, mental health issues, and what we found is that for family members, behaviour or challenging behaviour is consistently identified as the most problematic and burdensome consequence after a brain injury.

So the gaps in the literature that our study sought to address were that most of the study is looking at challenging behaviour after brain injury are more so in the early period post-injury, with few really extending on to the more chronic period ten, twenty years after brain injury, so there's a lack of knowledge around exactly what behaviour looks like at that point for individuals.

Also, the in-depth studies from the perspective of the actual individual themselves. Do they think their behaviour's changed? Do they think it's a problem? How do they think it's changed? And within that context, it's very important to also have an informant's perspective. Whether that be a family member, friend or carer. So firstly, to get a level of insight for the individual, but also to get their unique perspective as well and how that journey, living with or even caring for that individual with the challenging behaviour has evolved over time.

There's also a tendency for studies to focus in on aggression, anger, and low frustration tolerance, but recently, there's a great new tool called the Overt Behaviour Scale that I'll be talking about in a little bit more detail later, and that has provided us with some really fascinating information about behaviours across the categories, so all behaviours that I was mentioning before, social disinhibition, sexual inappropriate behaviour, and what it's shown

is that people do have behaviour in multiple categories, so it is a very complex situation, and that verbal aggression and social disinhibition are the most frequently endorsed.

Also, treatment. What are people receiving in the community many years post-injury and do they think it's helpful, and if not, why? What would they like to see happening?

So with all of that in mind, the objectives for our study was to determine the nature and the severity of challenging behaviour in individuals with moderate to severe brain injury, living in the community, obtaining both the perspectives I mentioned before, so the individual and their close other, and explore the service use and patterns.

What were the treatments they were receiving and how helpful did they think that they were?

So this leads me into the design of our study. We had a quantitative aspect and a qualitative, so I'll be discussing the quantitative and then Kate will present the qualitative aspect in the next lecture. So we had three participant groups who we interviewed, so the individual themselves, a close other who was mostly mothers, wives, and attending care workers, and we also interviewed clinicians, and that was mostly psychologists and neuropsychologists.

Unfortunately, we weren't able to obtain enough clinician perspectives to include them in our quantitative analysis, but we did include them in our qualitative analysis, so we'll have a discussion of that in the next lecture.

So we had a phone interview that canvassed a whole range of demographic variables, both pre and post-injury, accommodation, relationship status, psychiatric history, medical history, current psychiatric and medical issues, we also had the Overt Behaviour Scale which I'll discuss in a moment, and some objective measures, so that just refers to some brain injury severity data and the costs of their care as well.

So then the Overt Behaviour Scale, so just in case there is anybody who isn't really familiar with the scale, it's a thirty-four item measure that canvasses behaviour across those nine categories in the last three months, and it captures the severity of the behaviour in each category, the frequency that it's occurring, so from less than monthly to multiple times a day, and the impact, and that's the impact on people around them, also practical disruptions. For example, carers saying, I don't want to work with this person any more, and that can be all the way from no impact at all to extreme. And there are three important total scores I'm just going to go over quickly because we'll be referring to them in the results, so there's the cluster score, and that's just calculated by summing up the presence of each of those nine categories of behaviour. Total levels also comprises the number of severity levels endorsed, and then the clinical rate of severity incorporates the weight given to each severity level, so that has the most detailed information in it.

So the participants who we invited to take part were clients at the Transport Accident Commission, which is a No Fault accident compensation system operating here in Victoria, and everyone had to have a moderate to severe brain injury, be within those age brackets and have a TAC payment in one of those areas.

So the only important thing, really, to take from this slide is that TAC found just under three hundred people who were eligible, and then working down through people not being contactable or declining to take part, we ended up with sixty-five interviews with the individual themselves, and sixty-two with close others.

Some demographics, so to take away from this slide is that they were mostly males, they mostly had their injuries as adults, but we did have some paediatric injuries as well, and that based on GCS and PTA, it was severe injuries.

So the next two slides are broken down in to pre-injury and current, so you can see some of the changes. As you can see in the top row there, quite a degree of relationship breakdown has occurred after the injury, and also, a really substantial drop in employment, so if you just look at the fulltime row there, you can see it's gone from 60% to 8% who are now in fulltime employment, so quite a drastic drop.

Some more you can see here that psychiatric disorders have increased, as have medical disorders and pain. So pain is 60%, so you can already see some of those variables that I mentioned at the start of the talk that might be influencing behaviour, psychiatric disorders, medical comorbidities, pain, dislocation from accommodation, relationship breakdown.

Okay, so on to our behaviour results. So when we asked the individual themselves whether they felt their behaviour had changed, about 80% did think that their behaviour had changed since injury, and of those, about 80% again thought that that behaviour change was still current.

When we asked them to say in their own words, we asked both the individual and their close other, how did they think their behaviour had changed, how would they classify it?

We got words like angry, moody, mood swings, and also, a significant number of people saying, my personality's changed, but I'm not sure how to describe what's different. I know what's different, but I know that it is.

In terms of behaviour, support received of those with behaviour change, only 38% were actually receiving support, and it was mostly psychology and neuropsychology.

But they were very satisfied, which is very nice feedback for the profession, so mostly highly satisfied and that was true of both the individual and their close other.

When we asked them if they want to further behaviour support, we had about a third of people who weren't receiving any support, saying, yes, they felt they needed some more support, but interestingly, also of the people who were already receiving support, about a third were saying, I actually need more support, I need more help specifically targeted to my behaviour.

So we were able to do a comparison of responses to see how the responses from the individual and their close other were matching up, so we were able to do that on four questions related to their behaviour.

So the first one was simply has your behaviour changed post-injury?

A fair level of agreement and you can see from the key there, that's really towards the lower end, and that was mostly in cases where the individual self-reported no behaviour change, but the close other felt that there had been behaviour change.

Better levels of agreement for whether it was resolved or current, they agreed on that one, and also whether they were receiving behaviour support, there was a good level of agreement.

The lowest level was whether further support was needed, so again, most of these disagreements were where the close other was saying, yes, we do think that further support is really needed, and the individual with the TBI felt that they were tracking along okay.

So our obs results. Of our sixty-two close other reports, about 70% felt that their individual with the brain injury had behaviours of concern in at least one of those nine categories that I displayed before, and most commonly, this was verbal aggression, socially inappropriate behaviour and lack of initiation.

So these are the nine categories here. You can see, as they're moving through from most frequently endorsed to least, but down the lower end is self-harm, inappropriate sexual behaviour, and also wandering off or absconding.

In terms of the number of behaviour categories present, so the average was three, so most people were showing behaviour in at least three categories.

The important thing to take away from this slide, really, is that people were showing behaviour up in to the higher levels of severity, so it wasn't just that they had lower level of severity across a number of different types of behaviour, verbal aggression, socially inappropriate behaviour etc, but they were actually within the higher levels of severity across behaviours as well.

So what does this mean? Behaviour problems are present and significant many years following injury, so the sample was on average, eleven years post-injury, so this is over a decade after the injury, still seeing these behaviour problems. An average of three categories of behaviour, and that echoes really well with previous research in using the obs measure specifically, and again, our most common behaviours were exactly the same as previous obs research done both here and overseas.

The order of categories was also almost exactly the same which is quite fascinating, so our least frequent being inappropriate sexual behaviour, self-harm, wandering, absconding, again, marries previous research with the obs.

The thing that was discordant with our results and previous results, once we started to look at a more detailed level of the different types of severity within behaviour was that all previous research using the obs has found that sexual talk, so making inappropriate sexual comments is the most common form of inappropriate sexual behaviour. With our sample, it was non-genital touching which just means things like touching a shoulder or putting an arm around somebody, likely due to the injury severity in our sample, so a lot of communication difficulties in a small proportion of nonverbal individuals. We feel that probably is the explanation.

Really interesting high rates of self-reported behaviour change, despite they're still more likely to evaluate their behaviour as unchanged when compared to their close other, possibly due to some issues with self-awareness also may have been the nature of the question as we posed it, so quite a general question, asking them to think back and compare it with some of them over ten years, to a pre-injury self, but at this point, might've been largely forgotten or idealised.

In support of that hypothesis, I suppose, there was greater concordance on more specific questions such as, is it current or resolved, and whether behaviour support was being

received? So on that note, less than half are receiving support specifically for their behaviour, despite having TAC funding, and both the individual with the brain injury and the close other reporting that they want further support, and even for those already receiving support, they still were feeling that they needed more support, and again, that's consistent with previous research that's found that individuals with challenging behaviour have a higher proportion of unmet need.

So what's the takeaway from all of this? So ongoing support specifically targeted to behaviour, challenging behaviour is critical, because behaviour may be present often at severe levels many years after injury.

It's also important to target interventions across behaviour categories, not just at aggression and irritability, and it's really important to obtain perspectives of individuals with the injury, as well as their close other.

That's all. Thank you.

**(Applause)**

### **AMELIA HICKS**

Hi, so hopefully, that's given everyone a really good sense about, I guess, the extent of the issues with behaviour in that sample of individuals with access to TAC funding and perhaps that would've been a bit of a surprise to some people to see the sort of ongoing nature of those issues and the fact that many people do want more support or they're getting support and they're happy with it, but they need more, so it raises a lot of questions. It gives us a sense of the impact and the extent of the issues, but I guess one of the challenges of quantitative research is it doesn't get down in to sort of really understanding a topic potentially.

So I'll be talking now about sort of another part of the program where we actually ran a qualitative study which means getting a kind of in-depth understanding of a topic. It can be through a variety of means, but things like interviews and any other sort of information to pull together to get a richer understanding that really compliments the quantitative or more numbers-based research that we've done.

So you've already had from Amelia a sort of a definition of what behaviours of concern or challenging behaviours are, and how they can be really problematic in terms of consequences for the individual, for the family, but also, more broadly, they're very sort of challenging for clinicians to work with.

They're described in research as very confronting and difficult to sometimes know how to best support individuals who do display challenging behaviours.

They're also challenging for the communities in which the person lives, who perhaps is demonstrating aggressive behaviours when out, interacting with people in the community, and also, they're more challenging for funders who may feel that they need to invest more money towards attendant-care supports so that person has supervision when out in the community. So I guess across the spectrum, these are really important topics for us to understand and more importantly, to provide treatment so that we can reduce those impacts.

However, there isn't actually any strong evidence base for how do you support people and their family members for behaviour issues?

There are some very handy resources for inpatient-based practices such as [Mathies & Krautz's handbook, but arguably, that's not necessarily able to be implemented in a community setting where you don't have the control that you would in a hospital environment.

Also, as Amelia described, we're looking at people who are decades after their injury as well, so they may not be any more sort of linked in with support services and have access to specialised treatment.

The injury was years ago and some families might not really have that understanding of the association with the brain injury to even sort of reach out for supports at that late time.

So it's really important that we do start to get a deeper understanding of these issues, as that can really help us in designing effective and appropriate treatments.

In terms of qualitative research that's been done to date, those four behaviours of concern have really sought to ask the perspectives of family members and carers and clinicians on these topics and some really helpful studies by Tam, McKay, Sloan and Ponsford quite recently, brain, and also, a mixed method study in New South Wales that looked at quantitative and qualitative information based in New South Wales.

There's been one-focus group on just irritability specifically, not looking at the kind of broader range of behaviour and this study actually included individuals with brain injury in ten monthly focus groups which I think was a really novel design and very interesting findings. But to date, as far as we know, there haven't been any studies that have included the individual with the brain injury themselves in qualitative research looking at behaviour issues after brain injury. And as Amelia talked about, it is really important to get the perspective of the individual with the brain injury, and in sort of many respects, they were able to describe having behaviour change, so it does suggest that they are worthwhile people to include, they are the consumer as well.

So the aim of the study I'm going to talk about now is to understand the lived experience of behaviour issues and their treatment in a qualitative design which does include the person with the injury, their family members or carers and the clinician as well.

So we included individuals who have already been described in the study Amelia talked about, so they were clients of the Transport Accident Commission and we invited them to participate in this qualitative research if, on the Overt Behaviour Scale, there was any behaviour evident.

We weren't so much interested in talking to those individuals who didn't have behaviour issues.

We also invited participants of non-compensable settings through two ABI organisations and we asked the clinicians of those services to complete the Overt Behaviour Scale, so we could identify clients as well.

So as you can see here, these are our three participant groups.

We have the individual who sustained a brain injury, we have a close other informant, so a family member or carer, and a treating clinician, and we were able to conduct twenty-five interviews which is considered reasonably large for qualitative studies, the previous two studies by Tam and Braine included five and six interviews. And you can see here, we've got the person with the brain injury, their pseudonym over in this first column, then their close other, so you can see we've actually got a cross-section of mother, father, sister, carer, wife etc, and we also asked them to identify a clinician we could speak to as well and then we asked that clinician to participate and that just happened to be clinical psychologists and neuropsychologists, and you can see here also, if they were funded or non-compensable, whether they lived at home or in supported accommodation.

So just to tell you a little bit about our individuals with brain injury, they were all male, not by design. We did notice that the participants who had TAC funding were actually younger at the time of their injury and the interview than our non-compensable participants.

They were all in the severe range, in terms of the severity of their brain injury. For those with TAC funding, we didn't have injury severity information for our non-compensable clients, but they certainly were individuals with higher support needs. For instance, 80% of them needed assistance with personal care task, compared to none for TAC participants.

So in terms of what does the qualitative interview look like, it's a semi-structured interview format, and we use that to guide our questioning and then you kind of can ask further questions to sort of pull out the details of the topic.

The way that we asked those questions evolved over time as we reflected on the answers we were getting and sought to really sort of keep focused on specific themes that were emerging, so that's described as an iterative approach, and we asked, initially, the questions were largely around behaviour and the general injuries and treatments as well.

These interviews last from nine minutes with a very severely impaired individual up to ninety-five minutes, they were all done face-to-face, and they were recorded and then transcribed and proofread.

We were very mindful of the challenges that could be involved with asking individuals with cognitive and communication impairments to participate in detailed interviews. So we had a variety of strategies to try to mitigate those potential issues as you can see here, things like summarising and checking for clarity, making sure that we repeated information or simplified questions and conducted those interviews at a time that was really suitable for the individual as well.

The way that we sought to interpret the information we got from these interviews was using an iterative thematic analysis approach by Braun & Clarke.

This has six stages that essentially guide you through familiarisation with the data through repeated readings, generating codes which are sort of short excerpts of the data that we used computer software to organise, then we identified from those codes themes that help us sort of capture a group of those codes, and we go through a process of reviewing and refining these with lots of discussion and lots of reading back of the transcripts, until you get to the point where you can sort of really define and name a theme, and the last step is to really

identify some key quotes that illustrate those themes. And the last point is just a sort of technical point about how we understand reality.

There's a lot of philosophising that takes place as part of doing qualitative research, and our assumptions weren't there, but there is a reality that exists outside of our observations, but that it can be influenced by our language, our culture, our professional background etc, in shaping our interpretation of that reality.

So I conducted the sort of initial coding structure of how we labelled the different comments that were coming out of the interviews, and Amelia who also conducted some of the interviews, then went back and coded against my structure. So we wanted to compare how we were using that coding structure and that came out as a substantial agreement which was very encouraging, and if there were things we disagreed on, we just talked that through till we could come to a consensus.

We also wanted to make sure another sort aspect of our rigour was that where we came to with all our sort of discussions and interpretations actually matched what the individuals had originally tried to tell us. So we went through a process called member checking where we had a few aspects to that, so for example, at the end of each interview, we'd sort of check back that we'd sort of captured what they were trying to tell us.

After we'd been through some of the analysis, we also spoke again with the individuals with the injury and checked that we'd captured the kind of key points from their discussion and gave them the opportunity to feed back in to our analysis, and at a more detailed level, we sought the input of clinicians and key stakeholders as well.

So then we come to the actual findings of our qualitative research. What we came up with was this sort of framework that summarises the key themes that we discovered. So we've got behaviours of concern in the middle, and then we've got seven themes that relate to behaviours of concern in both directions, and also, are linked in with each other.

So what I'm going to do now is I'm going to go through each of those eight shapes and themes, and provide you with a pretty brief description of what each of those mean, and a couple of quotes.

The qualitative research can become very detailed and very complex, so it is a bit of a challenge to compress it in to a short talk, but I can let you know that this research has just been accepted for publication in *Neuropsychological Rehabilitation*, so you will be able to read a more in-depth version of this, although it never seems in-depth enough for all that we want to say, so we could write a paper about each of these themes very easily.

So this is the first sort of central theme, behaviours of concern.

One thing that was quite apparent early on is that the people who we spoke with who are living in the home setting, so they were individuals with lower support needs.

They were quite aware of their behaviour issues and they described these issues to us without any kind of necessarily shame or embarrassment, it was just very matter-of-fact, I hit this person, I lashed out, so that was really interesting.

The individuals who are living in supported accommodation who arguably had higher support needs, they weren't necessarily as able to communicate their behaviour issues specifically, so we had reports about their behaviour, predominantly from the informants.

So I've got some quotes here about an example that I just said, the very matter-of-fact manner about, I've got a short temper, I'm aggressive, if someone pushes me, I'll just hit them.

In terms of the nature of the behaviour issues, we found that all participants, there were descriptions of verbal and physical aggression, and challenging social interactions which really ties in with what Amelia's talked about as the kind of key behaviour areas.

For those with those higher support needs, though, we discovered a broader range of behaviour issues as described there.

Interestingly, there wasn't a clear consensus of the pattern of how behaviour issues emerged over time.

For some people, things were getting better, for some people, things had gotten worse over time, and for others, things fluctuated.

When people did describe that there had been improvements, the individuals with the brain injury said, I made a difference, I'm the one who was active and the kind of primary instigator of these improvements, and similarly, the close other said, I'm the one who had made a difference.

They did all recognise that professionals had some role, so that is some encouragement, but I think that's really interesting and it's probably a perspective that we may not have heard before, particularly from quantitative research to date, and given the fact that no-one's done this sort of level of research with the individual with the brain injury does provide us with that kind of unique perspective already.

So I'll just go through a couple of the behaviour groups and what people were describing about this. So verbal and physical aggression, these are some quotes all relating to Sam, about how he lost it at Centrelink and he was worried they were going to call the police and his dad, John, said much the same.

He had real concerns that he was going to end up in jail because of this type of behaviour. Will was Sam's psychologist who again uses very similar language about Sam lashing out at people.

In terms of socially inappropriate behaviour, that kind of presented differently, depending on the level of support needs of the people we interviewed. So for those who were high functioning, living at home, getting out in to the community, they were quite aware of impaired social skills, things like rambling, getting off topic, whereas for those who were living in supported accommodation, impaired socially inappropriate behaviour may have presented like refusing to accept treatment, being impatient, inconsiderate or attention-seeking behaviours like refusals.

So that gives you a bit of a sense of the kind of patterns and the presentations of behaviour issues.

Moving on to the first theme, I guess a really important theme is the brain injury and that we can't forget that these behaviours are very much associated with the brain injury, and the way that came through in these interviews was particularly in regards to the cognitive changes as a result of the injury. Things like memory impairments which were very frustrating for people to experience, as well as black and white thinking or reduced insight. In fact, as well as that perhaps being a contributor to the experience of frustration and then leading on to behaviour change, that was actually a barrier for some people to actually being able to even engage in therapeutic, so Stewart, a neuropsychologist does say that because of the individual's rigid and fixed mindset, he's really struggled as a result of that, and in therapy as well.

So the next topic is control.

Now like many of these topics and these themes, there's a kind of multidirectional relationship, so feeling a loss of control or feeling controlled was a trigger for individuals to, for example, lash out or engage in attention-seeking behaviour, but it was also a really interesting way that people described a behaviour as well.

They talked about losing control, and on the other side, in a kind of more helpful sense, it could be a pathway for reducing control, so this is Joyce describing kind of both of those aspects, that lack of control leads to the behaviour, but also, when he is engaged in choices and being able to have some control, that makes a really big difference and that actually guides intervention as well.

In terms of the theme of our environment, we described this as really in terms of particularly those in the supported accommodation, those routines and the structure and the consistency was very important, and that when there was a lot of change in the environment, that this could lead to behaviour issues.

Owen says that he really likes the same thing with his carers, he gets in to a routine, he doesn't change from that and Michelle also describes the consistency of a carer program being really pivotal for Leon's wellbeing.

For our theme of mood, this captured a range of psychological aspects like depression and anxiety, but also things like the anger, stress, grief and difficulty coping with life stresses as well, and again, this kind of works both ways.

So this was an interview I conducted with Sam who I hope you'll be able to see was quite distressed, while we were talking about his behaviour. He's talking about how he's not able to deal with it, he's furious, he's shaking, he's not able to sleep as well, and that was a real sort of background to behaviour issues emerging or being triggered by incidents when they were frustrated. And again, reciprocally, when people were in good moods like this quote from Ross, then that has a direct impact on behaviour as well and better behaviour.

The next theme was social relationships and I guess this is pretty understandable, but an individual who is aggressive or has poor social skills or has sexually inappropriate behaviour, people over time don't want to socialise with that person. In a very striking example, Peter actually punched his friend, a good friend, right before the friend's wedding, and his face blew up like a peach, and after that, they didn't have quite the same level of relationship, quite understandably.

But also, being aggressive just gets in the way of communication as well. And the theme of social relationships also reflected a change in social roles, so there were instances where a wife would say, because of my husband's behaviour change, he's not my husband any more, I'm more like a carer, or because of my brother's behaviour change, he can't babysit his nephews any more, he can't be trusted to remain calm when they act out, so that had a clear impact on their capacity to engage in those meaningful social roles as well.

On the other hand, individuals who were socially isolated perhaps because of their behaviour or for other reasons, that also led to some unhappiness about that situation which again could trigger the behaviour issues, so it kind of works in a bit of a cycle. And the theme of social relationships is very much tied to this other theme of meaningful engagement.

So individuals had a clear purpose with their life and with their time, they were doing things that they got value from. That was really important and an actual direction of therapy and I love this quote from Amy, a psychologist, who described how Jack went from throwing furniture around to actually making furniture.

So for example, for individuals with physical aggression, like Jack there again, that impacted his capacity to get a job.

On the other hand, sometimes the behaviour was a barrier to their participation. For example, Sam was doing a security guard course and he's very aggressive, so that's clearly sort of not appropriate and not suitable as well.

Building on from those topics of meaningful engagement and social relationship comes a theme of identity and I think this was a really interesting finding of our study.

There has been a lot of research on identity and brain injury, but not that it's brought in behaviour issues as well. I think this is a theme that you can only really capture by asking the individual themselves.

We found a lot of instances of the person with the brain injury describing how their sense of self had really changed, who they were before and who they are now.

Before my accident, I was quiet, now I'm the loud person at the party. I don't mean to yell, and John describing how his son, Sam, had behaviour traits that were really galvanised and reinforced or exacerbated by the injury as well.

This theme was really complex and very variable, and not only was the behaviour resulting in a change to the person's identity or the lack of ability to engage in meaningful activities, changing their identity, but also that for instance of self could result in a lot of grief and distress and frustration.

So that kind of gives you a bit of a nutshell overview of these key themes, and I thought it might be helpful to go through a couple of examples that kind of demonstrate some of the complexity and the interactions of these themes.

So in this first scenario, this is about an individual who lives in supported accommodation and there's a high staff turnover and there's an agency staff member who starts.

So that's been a change to that person's environment and their routine. There's the loss of the familiar staff member and those sort of supportive relationships and known relationships that

might lead to attention-seeking behaviour in an attempt to try to get some sense of control out of the individuals day to day where things have been happening out of their control like new people coming in to their life and perhaps providing an inconsistent degree of support. And then that kind of loops around, again, in a sense, that person's behaviour might change what has to happen in their day, they're no longer able to engage in the activities that they were planning on doing because of a behaviour incident.

In another example, this is about an individual who is living at home, has lower support needs and is attending a party and gets overwhelmed.

They get angry and frustrated that they can't keep up with the conversation or they can't remember what everyone's been talking about.

Then the individuals, either by the person with the injury, and it could be by their own accord that they choose to stay away from people because they've been acting impulsively or aggressively, or that the people in their social network stop inviting them to parties and stop socialising with them. That could mean a loss of meaningful social activities like going to parties or playing with your friends in a regular football match. The loss of that meaningful activity or that sense of purpose about your time does impact then your sense of self, how you see yourself, maybe I'm no longer a footy player any more. Who am I? Am I this angry person who doesn't have friends, and then that's very confronting and that leads to more anger and more frustration and a cycle again.

That then provides that perfect background for getting angrier and leading to yelling or threats.

So in summary, despite talking to a number of people where we got very individualised accounts. We were able to pull through some common themes, but it was very complex, there was a high degree of interaction between all the themes that were related to the person as an individual, to their injury, to the social and environmental factors as well.

We did find that we could see some trends in those with higher support needs compared to those with lower support needs.

Those with higher needs had a broader range of behaviours and we saw more discussion of the impact of environmental change on their behaviour. They tended to have less awareness or less capacity to communicate their behaviour change, and less capacity to control themselves in that environment.

For those individuals who had lower support needs, those tending to live at home predominantly, they had a greater degree of awareness of their behaviour issues. They were able to describe to us how that impacted on their identity, and they were engaging in slightly different behaviours or different sorts of presentations of these types of behaviours.

What we have found is largely consistent with those of other findings and other research, particularly those studies on caregivers, that there is a really concerning impact on caregivers, how they see their roles in relation to the person with the injury or the degree of distress about the consequences of these behaviours, will my son end up in jail, and the fact that those behaviours were often directed towards those caregivers as well is very confronting.

In terms of research that's been conducted looking at clinician perspectives, we see again similar themes emerging around the factors which develop and maintain behaviours like the clients' characteristics, the families and carers, the environment, as well as what are the consequences of the behaviours on things like family adjustment, contact with criminal justice system and participation in meaningful activities?

So to conclude, I think that some of the strengths of this study are that we did include the individual with the brain injury and we were able to capture meaningful information from those interviews, suggesting it is really worthwhile and valid to do so. And there's a kind of broader trend, not just in brain injury, but across the board of including the consumer, really actively in the design and the research of their own issues and treatments.

We were able to triangulate those themes between the person with the injury, the clinicians, the caregivers and family members, which is a strength of the study as well. We had a large sample size, we can provide some guidance for clinical interventions based on what people have told us and we've captured a broad range of experiences as well.

Now any research isn't without its own limitations, so just as it happened, all our participants with brain injury were male, and it may be that women have a different experience after brain injury.

Some research suggests they have better outcomes, so that isn't captured by our research.

There were a couple of participants who were too severely impaired to be interviewed, so we weren't able to capture their perspective on their injury.

When we asked our participants to nominate a clinician, they all happened to be psychologists. So again, that's one aspect that might not reflect, for example, OT's or physios or speechies, or case managers' perspectives as well on the behaviour. And also, we have to be mindful that Amelia, myself and Jenny Ponsford, lead authors on the study, we all have a background in neuropsychology which can also sort of taint our perspective on interpretation.

That being said, I think that we can take some clinically meaningful information and implications from our findings.

I think going through our findings, it suggests that it's really important that individuals are able to exert a sense of control or at least controlled choice in their environment.

That there's a sense of routine and consistency, that any issues with mood are able to be supported and treated appropriately.

That we include the individual when we're asking about behaviour treatment as well and identifying what is important to them, what matters to them, how does that relate to their sense of self, to the activities that they want to participate in?

As we know from research like Tam and Braine's how important those meaningful life roles are in shaping a person's identity and we would argue and in reducing behaviour issues as well.

We need to include the other people in their environment and this may not just be the staff or the family members. There are other people in the environment who can have an active role in the person's intervention as well.

They could be, for example, guitar teachers or other individuals where they can perhaps get a sense of social relationships that they might not have access to otherwise.

We need to be mindful of the impact of the behaviour on the caregivers and family members and how that impacts relationships, roles, and the caregivers' sense of distress as well and we would argue that providing support to those individuals could also help behaviour change issues as well.

When we do instigate any intervention, that does need to be modified for the cognitive impairments and the level of insight and awareness that the person has.

This can evolve over time, so we think that interventions need to be sort of modified and scaled up or scaled down as the individual progresses over time.

In terms of where you as therapists can sort of look for appropriate sort of therapy modalities, as we said at the start, there isn't a clear evidence base yet for what this therapy should look like, but a therapy called Positive Behaviour Supports by Mark Ylvisaker, Tim Feeney and colleagues does sort of tick the boxes of what we've been describing, because it's sensitive to the person's context and their environment, it's individualised, it includes people in an individual's natural supports, and it focuses on meaningful participation and roles as well.

So just before we sort of finish off on our discussion of this phase of the research, I guess it's important to let you guys know that this was an early sort of phase of a study where we are now in to the next step which is actually to evaluate a therapy for behaviour change after brain injury, and I wanted to tell you a little bit about that study in brief because we are actually hoping to have recruited more referrals to our program, so I can tell you a little bit about that and then maybe we can go on to some questions in general discussion.

So we are conducting this trial of Tim Feeney's and Mark Ylvisaker's positive behaviour support approach. We have Tim Feeney on board with us as a clinical mentor and an investigator on this program where we're providing a year of free interdisciplinary therapy by ABI specialists to evaluate and build on to this sort of stronger evidence base of is this effective for individuals with brain injury?

So people who participate get randomised to receive a year of therapy straight up or go in to a controlled condition where they receive their treatments as usual for a year, and then commence a year of therapy and then we follow up individuals over a year follow-up period as well.

So we're interested in people with any kind of brain injury although this research we talked about was just traumatic brain injury. We are interested in people with other kinds of acquired brain injuries like stroke or hypoxic injury, we're looking at adults who have any level of current behaviour, so any of the behaviour issues we just talked about, they can be very mild or very severe, and they need to have an informant like a family member, a carer or other therapist who can help us with the research measures although we will of course be asking the person with the injury to do them as well, but if the person has communication difficulties, they can still participate. Obviously, we don't need people who are already actively receiving great behaviour programs to the study, they are welcome to continue with that, but you might know of some people, particularly without compensation funding who might be really suited to receiving this program.

So that's a little bit about that next phase and it's a very exciting program, it's funded by ISSCR who have funded us the whole way through, and we look forward in a few years' time to share the results of that. As it's a randomised controlled trial, we can't evaluate the intervention until the very end, so that's at least three years away, but we've been going for this program already for over a year and some very encouraging results so far. So that's that.

**(Applause)**

*So I'd really just like to open it up, but I guess I think I'd just like to make a really positive comment as someone who loves qualitative research, that it was so lovely to see such a nice mix of both quantitative and qualitative, and that sense of the rich information you can get from the person who's had the experience themselves which was really lovely to start bringing in to the picture. But for me, I really like your end model because I think, I was looking at that and thinking, it's a really nice conceptualisation for me as a clinician to sort of be looking at each of those little circles on their own and go, what's happening for this particular person and giving me a framework to start thinking about them, so that was just some of the comments that I had.*

*Thank you, thanks very much, Marg, yeah, that's what we hope that model isn't kind of new and unusual, but everyone's going, yeah, well, of course, that makes sense and that fits with how I think about behaviour as well, that's a really good bit of feedback for us if that is the case, if it's not, if this is very different to what your conceptualisation is, we're interested in that, too. I guess one day, when we write up all the papers for each kind of circle, we'll be able to kind of pull out, there are a whole range of other factors that feed in to each of those, so we haven't ignored things like pain. They just fit in to the injury, for example, but it's very hard to sort of capture all of the complexity and I guess balance that with something that captures the kind of key essences of those as well, so we're interested in your feedback as well about whether you think that that rings true.*

*Q: I just love, again, that diagrammatic conceptualisation because it mightn't use exactly the same words, but I always think that's great to sit down with patients and they really get it when it's done in that way, so it's great.*

*Thank you, yeah, so that diagram will be in the paper as well, yeah, Pam.*

*Q: Just from a return-to-work aspect, I'm just interested because you obviously think that if people had a meaningful activity in their lives, then they're going have less behaviours of concern, I guess, but were any of the participants in there, did any of them have any kind of environment where they-?*

*Yeah, so they did have individuals who were working. The one individual I can think of, he had sort of sporadic work, but that was incredibly important to him and his identity, and probably also helped his relationship that he wasn't there all the time.*

*Yes, I was wondering if you felt his behaviour improved when he was engaged in work, it was different, wasn't it?*

*Definitely, that individual I'm thinking of is actually in our treatment phase. We have three individuals from the qualitative phase in our treatment and it actually happens that he's no longer in work and his relationship has broken down and the behaviours have escalated, so not surprisingly.*

*Q: Yeah, so it's important, it's great that he's got extra funding, but it'd be lovely if that could, if we could do something more about providing opportunities for the ones you were talking about.*

*Yeah, and we're really mindful of that, that this research that we're doing has the opportunity to feed back to funding agencies because TAC are behind ISSCR to say, this is important, behaviour issues don't go away over time, they need this kind of comprehensive input. People are getting input from a funded body, and they're happy with it, but it's not really resolving the issues and that's a really key point and not probably what TAC want to hear, but that's what we found.*

*Q: I thought it was interesting that so many of them were still getting neuropsychology because they had behaviour and they were getting neuropsychology, but the other factors that you were talking about were being missed out on down the track, so great feedback that TAC had.*

*Yeah, it really requires a kind of comprehensive and integrated approach, yeah, thank you.*

*Q: I was going to say that the impact of long-term behaviour from neuropsych that I can find that people be referred as inpatients, they'll go to a hospital team and they might refer to a community therapy team for a little while, and eventually, they'll discharge and then we get referred clients three, four, ten years later and behaviours have come up again or the new behaviours or the old behaviours that have had some treatment and kind of they've had new carers on board and they've reverted back to their old behaviours and by then, they're so hard to use the new ones who are being treated and because of the time and all the carers just give up and do what they want to do and it's that whole, so we're so lucky to have TAC to say, that's fine, another therapist to try and get that, but I think as a community therapist, I'm learning that when you're discharging someone, we almost just apply for funding once every three months, just to keep an eye on things, but it just keeps them going.*

*Yeah, absolutely, and that's something we're really mindful of in how our research therapy trial is interpreted, that we're not saying a year of therapy is enough to tick all the boxes, but we're hoping that an intensive year that has a focus on long-term sort of coaching of natural supports so that the people in the person's long-term environment have tools to help that person, but that will stem it to some extent, but there is always an expectation that life will happen, someone will die, a job will get lost, carers will change and that people do need ongoing episodic input, and that these problems aren't going away over these decades.*

*Q: The relationship changes so they're happening due to some child and then the child becomes a teenager and then their life or relationships break up and things are always changing.*

*Yeah, that's right, so hopefully, this does provide I guess one extra aspect of the evidence for what community clinicians are experiencing and that can then form an evidence base for why we're doing what we're doing in the community treatment sphere.*

*Q: I wanted to ask, sorry, Amelia, about the findings of the obs, did you find or did you get time to look at any relationship between the pre or post-injury factors that correlated with the nine categories?*

*Yeah, we would've loved to. Unfortunately, the sample, so we tried to do a regression with clinical weighted severity as the dependent variable, but two things. The sample was so small and the variation on that total score for the obs are so small that statistically, we weren't really able to do a regression, but certainly, if we had more data, that would've been something that would've been really interesting to do.*

*Q: Yeah, and are you dealing with a trend?*

*Well, we did actually do the regressions first and had a look at them and there was nothing, so unfortunately, yeah, that would've been very interesting, but it's a great idea.*

*Q: Yeah, I just feel like when you see the less common things like the self-injury and the sexual disinhibition and things like that, I feel like it's people who have had pre or post-injury and psychiatric problems, that's the feeling that would be good to-.*

*Yeah, we're collecting more data as part of the intervention, so whether we could put that together with this data, we'd have then something like a hundred obs, and then look at those factors, absolutely, it's a great idea.*

*And you might want to look at Graham Simpson's group on the New South Wales report. He was one of the authors of the Overt Behaviour Scale, so he has a very comprehensive report, there are the journal articles, there's also a government report as well on factors associated with the obs as well, so that might be helpful.*

*Q: Yep, any other questions?*

*I'm interested, if anyone disagrees with anything we've presented, this is a pretty biased audience, I think.*

*Q: What sort of support were any of the caregivers getting?*

*So there were some, there were actually individuals who were getting lots of support, there was a wife who was in an ABI carers' group and there was a carer who had done ABI training support as well, but they all wanted more, absolutely*

*And many of them reported just receiving booklets or links to websites to look at during the inpatient period and that was the extent of it, so there was a real mix,*

*And I think also, potentially, you can't ignore that they are, there could be a bias, those people wanted to participate in this as a research study, they kind of are motivated individuals, so there may be many individuals out there who aren't interested in more support as well.*

*Q: And continuing the study, are you still going to look at identities?*

*So the purpose of the next phase of the study is evaluating the intervention. As one of our intervention practices, we do a technique called identity mapping, so we do record how often we do that and we ask people what their experience of the intervention including that is, so that will be a part of it, and I actually found personally that the topic of identity was absolutely fascinating, Jacinta Douglas and Tamara Owensworth have done a lot of work in the area and it's so interesting and I do believe the qualitative research really opens the door*

*to those sorts of discussions that you kind of really can't get the same sense out of a questionnaire, for example.*

*Q: Did you find that self-identity was more positive or negative?*

*Well, we didn't try to kind of dichotomise it in that way, but I certainly think it was more associations with, for example, meaningful engagement was a really big part of people's positive social identity. I like it when I do my gardening, I like going to the pub and playing pokies with my friends, and those sort of identity and meaningful participation and social relationships really strongly intertwined as well.*

*And there's also a degree with people who had self-awareness, there seemed to be some identity protection going on, so talking about well, that's not me, that's my injury, I don't really have control over that, so that was another interesting aspect of identity that came out.*

*Yeah, I'd just like to touch on the randomised control trial we're doing, it's actually taking referrals until the end of March, so if anybody did have someone in mind, the cut-off is the end of March, so please get in contact with either of us.*

*And that does unfortunately mean that they have to be in the study and seen by Amelia for a baseline appointment as well. Yeah, so if you do have any thoughts like today, absolutely.*

*Just give us a call, or shoot us an email, we'll get on to it.*

*Q: How do you rule patients?*

*Yeah, we're taking, we initially wanted just to take people an hour away, but we have opened it up state-wide and, for individuals who can manage with teletherapy, we do have a clinician in Sheparton as well who can do some of that region and we're very interested in referrals for that area, particularly, but we can chat through any specific individuals who you might want to talk about.*

*Thank you.*

*All right, can everyone put their hands together and thank Kate and Amelia?*

*(Applause)*

**END OF TRANSCRIPT**