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Athletes with Neurodegenerative Disease: A Phenomenological Exploration of Family Members' Experiences

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**Abstract**

This qualitative study involved in-depth interviews with 15 family members (mainly partners and children) of deceased athletes who experienced deterioration in their neurological health towards the end of their life. The purpose of this study was to examine the stressors these family members experienced with the ailed players, their emotional responses to their family member's condition, as well as the coping strategies they used. Vertical and horizontal thematic analyses were conducted on the data, which revealed five distinct temporal stages, a range of emotional responses, as well as accompanying stressors and coping strategies at each temporal stage. The findings are presented as an ethnodrama, capturing the lived experiences of participants. This ethnodrama aims to resonate with those caring for family members who are experiencing deteriorating neurological health, while also raising awareness of the various emotional responses of the individuals in these situations, as well as inviting dialogue and reflection about these issues.

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## Introduction

Traumatic brain injury is commonplace in sport, with collision sport athletes at particular risk (e.g., Adams et al., 2018; Standring et al., 2019). Unfortunately, however, these injuries may also result in short-term and potential long-term consequences for athletes. For example, Metz et al. (2017) reported that 99% of National Football League (NFL) players' brains showed signs of neurodegenerative disease when autopsied. Yet, despite rapidly growing neurological examinations of athletes for various forms of traumatic brain injuries, only a limited number of qualitative studies have examined how neurodegenerative disease can impact on family members of athletes (e.g., Faure & Casnova, 2020). As such, the purpose of this study was to contribute to this under-examined, social domain of traumatic brain injuries, by providing a thorough examination of the experiences of family members of athletes with neurodegenerative disease. Specifically, using partners and children who have experienced an athlete go through severe cognitive and behavioral decline before dying, we sought to understand the challenges, emotional responses, as well as coping strategies, not of the players, but of the family members living through these experiences.

Quantitative researchers have found evidence of the burden placed on those living with and caring for those with brain injury. For example, in a longitudinal study, Pillemer, Davis and Tremont (2018) surveyed participants and found that dementia caregivers suffered feelings of guilt, frustration, and depression, with these responses stronger in females. These findings supported previous survey research (e.g., Brooks, 1991; Brown & McCormick, 1988; Curtiss et al., 2000) that highlighted how the stress and burden felt by family members intensified as time passed from the injury occurring. Family members also reported challenges of uncertainty surrounding the illness, as well as highlighting the need for greater understanding from health care professionals, alongside support from others while they lived with this uncertainty. Furthermore, Riley (2007) surveyed carers of people with traumatic brain injury and found higher levels of stress and depression when

the behaviors of the athlete were more severe. Overall, these findings identify the range of challenges that family members experience as a result of traumatic brain injuries.

While quantitative studies have provided evidence of the burden on carers, there remains limited qualitative research examining the experiences of those living with people affected by traumatic brain injuries. Outside of a sporting context, Duff (2002) interviewed 25 family members of people who suffered a severe traumatic brain injury, examining the experiences of these family members following the illness of their 'loved one'. Findings highlighted the difficulties caused by the uncertainty of the situation, in terms of both the trajectory of the illness and how to support and deal with the cognitive, physical and behavioral outcomes exhibited after the injury. They also identified some of the challenges experienced, such as negotiating appropriate treatment for the person, as well as the increasing emotional and physical exhaustion of dealing with these difficulties. More recently, research has examined the experiences of those close to athletes who have traumatic brain injuries in sport. Indeed, Faure and Casnova (2019) interviewed 20 wives of American football players who were either currently playing or had retired from playing in the NFL. Findings revealed concerns about the cognitive, emotional and behavioral decline of these players. Wives identified behavioral changes that included their husbands becoming enraged, reduced positive social interactions with family members, as well as various erratic behaviors (e.g., starting risky business ventures). At the same time, deteriorations in cognitive functioning revealed that those affected by traumatic brain injury were no longer able to carry out simple household tasks and often struggled with language problems (e.g., misspelling regular words). Wives also reported the emotional toll these changes took on both themselves and their families, which included increased feelings of strain as a primary caregiver, feelings of exhaustion, as well as the guilt of not understanding fully what their husband was going through, alongside the regret of feeling they could have dealt with the situation more effectively.

The work of Faure and Casnova (2019) highlighted the emotional toll on family members following traumatic brain injury in sport, as well as a need to consider emotional responses more fully. Lazarus (2000) defined emotion as “an organized psychophysiological reaction to ongoing relationships with the environment, most often, but not always, interpersonal or social” (p. 230). Emotions are aroused when events are appraised as pleasant or unpleasant and, in any stressful situation, people may experience multiple emotions (Folkman et al., 1986). Lazarus (1999) also highlights how emotions are shaped by the appraisals made, how coping can impact emotion and how effective coping may trigger positive emotions (and vice versa for negative coping). Here, coping is defined by Lazarus and Folkman (2004) as deliberate cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as stressful. Researchers have also investigated how athletes emotionally cope in elite sporting environments. For example, research on youth swimming (Hayward et al., 2016) is used to inform practice about how best to support athletes in coping with the demands of their sport. Lazarus (1999, 2000) further proposes how stress, emotions, and coping are inter-related psychological variables, and suggests that researchers should avoid examining these constructs in isolation. Multiple sport scholars agree, suggesting that these variables be examined together (e.g., Nicholls et al., 2009; Nicholls et al., 2010).

In the current study, we focus on the emotions and coping, not of the athletes, but of family members who lived with an athlete with neurodegenerative disease. Similar to previous research (e.g., Duff, 2002; Faure & Casnova, 2019), we sought to understand the emotional responses and coping strategies in dealing with the demands of this challenging situation so that we might learn how to better support carers dealing with these demands, while also supporting their own emotional well-being. Yet, while the work of Faure and Casnova (2019) has advanced our understanding of the experiences of family members living with players who have traumatic brain injuries through playing contact sports, the generalizability of these findings is somewhat limited. For example, only

wives of the players were interviewed, and only the wives of players who have played sport (i.e., American Football) at the elite level were included in their study. Also, much of the wider traumatic brain injury research in sport examines males from elite sport, but amateur athletes represent the majority of the playing population. A further limitation is how Faure and Canova's work considers experiences holistically rather than examining emotional responses at different stages of their husband's suffering following brain injury .

Thus, the current study has two specific aims. First, this study adds to the limited amount of qualitative research by examining the experiences of multiple family members of athletes from the amateur to professional level. Second, this study investigates the changing nature of participant responses over a period of time in an effort to capture temporal phases in the analysis. Specifically, in the current study, the athletes go through a lengthy period of time (years) whereby their cognitive functioning decreases and they eventually die, meaning the family members themselves also experience an extended period of time with the athlete during their decline. Thus, we hope that understanding the emotions and coping strategies employed by family members at different timepoints will allow the findings to be used to support other family members who are at various stages of living with, and caring for, an athlete who has neurodegenerative disease. At the same time, the findings of this research may help policy-makers (e.g., the governing bodies of various sports) to raise awareness about how to support family members of athletes with neurodegenerative disease, as well as various charities, such as the Concussion Legacy Foundation, who have a stated mission of supporting all who are affected by such diseases. In addition, while much previous research, and the current study, has been conducted with a North American sample, the issue of athletes suffering from neurodegenerative disease is pertinent to sport participants throughout the world, meaning our findings have global importance for supporting family members.

## **Method**

### **Context, Design, and Philosophical Underpinning**

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Participants were recruited through ‘The Legacy Family Huddle’ (hereon in referred to as ‘The Huddle’) which is an event organized by the Concussion Legacy Foundation (CLF). The CLF is an international not-for-profit, which aims to support athletes affected by head injury, and to assist patients and families by providing personalized help to those struggling with the outcomes of brain injury. The aim of ‘The Huddle’ is to communicate understanding (e.g., research findings) of the effects of brain injury to family members, as well as presenting initiatives that the CLF have implemented. ‘The Huddle’ also allows families to connect with one another, providing an opportunity to share stories, build relationships with others who have similar experiences, and offers a source of peer-support.

A qualitative research design was used in the present study. Specifically, members of the research team attended ‘The Huddle’, engaging fully with the event, and interviewed family members. To allow for an in-depth exploration of the family members’ experiences, a phenomenological methodology was used (Thomas & Pollio, 2002). Here, Dale (1996) suggests that the aim of such a phenomenological approach is “to arrive at a rigorous description of human life as it is lived and reflected on in its first-person concreteness” (p. 309). Following analysis of data, we then used creative non-fiction techniques to present our findings as an ethnodrama. In conducting this research and presenting our findings in this manner, our particular interest was to understand the experiences of individual participants within a complex social world, while they were dealing with the death of a family member. Thus, this study was also underpinned by interpretivism; ontological relativism and epistemological constructionism, which allowed participants to share their individually constructed reality of living with an athlete with a neurodegenerative disease. We also acknowledge the active role the authors played in the co-construction of knowledge of a phenomenon that cannot be directly observed, through the analysis and presentation of data, as well as the steps taken to enhance methodological rigor.

## **Participants**

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Criterion-based sampling was used to recruit participants, aligned with the criteria for attending ‘The Huddle’. Specifically, participants were relatives of an athlete who had died, with the death linked to traumatic brain injuries from playing sport. The overall sample consisted of 15 individuals (13 females, 2 males), aged 17 to 73 years. Of these, eight participants were the partners of a deceased athlete, one was a sister, and six were children of an athlete. One athlete was a competitive lacrosse player, and the other athletes primary sport was American football. Their age at death ranged from 47 to 74 years of age and all of them had a pathologically verified diagnosis of Chronic Traumatic Encephalopathy.

### **Procedure and Interview Guide**

Contact was made with the CLF, and a relationship was built up over various meetings. This led to an agreement for a team of five researchers (authors one, four, five, six, seven) from the United Kingdom to attend ‘The Huddle’ - which was a three-day event in February 2020 that took place in Orlando, Florida - and conduct interviews with participants about their experiences. At the start of the event, the researchers were introduced, the purpose of the study explained, and delegates were encouraged to contribute to the research project by speaking to one of the research team at a suitable time during ‘The Huddle’. The researchers were each given a delegate badge and engaged in various sessions, which gave an opportunity to interact fully with the participants. These interactions allowed trust and rapport to be built up between the researchers and participants, and also gave the researchers a greater insight and understanding into their world. Interviews were organized at a time suitable to the participants, around the event schedule. This study was reviewed and approved by the University of Winchester Research Ethics Board.

The research team met on various occasions prior to travelling to the event, in order to plan the research project, and to construct an interview guide. Interviews began with the researcher outlining the purpose of the study, to understand participant experiences and, in doing so, help others who are having similar experiences. Emphasizing this purpose further enhanced participant

buy-in to the study, as participants wanted to help others learn from their own experiences. In line with having a motivated demographic, the interview started with a very broad prompt of “tell me your story” which allowed participants to take control of the interview, and talk about their partner, sibling or parent, while guiding the conversation in whichever way they wanted. At the same time, the interview guide included a series of follow-up questions, such as asking about how the symptoms of the neurodegenerative disease progressed, and any subsequent changes in behavior, as well as the way in which the participant themselves responded to the situation. Pertinent to the current study, participants were asked about challenges and emotional responses, as well as the coping strategies they employed, including the support (or otherwise) they received. The researchers each kept a reflective diary to record their ongoing responses to the research process, as well as meeting up at regular intervals during the three-day event. This allowed the team to support each other, as many of the interviews were lengthy and involved listening to emotive topics, with interviews lasting from between 40 and 101 minutes ( $m_{interview\ duration} = 66$  minutes).

### **Analysis Strategy and Representation**

In line with the recommendations of Braun et al. (2016), the second author conducted a thematic analysis of data, which initially involved immersing themselves in the data by reading and re-reading the interview transcripts, before deriving initial open codes, highlighting features of the emotional responses described by participants. Alongside this, stressors and coping strategies were coded and aligned with the relevant emotional response. Data applicable to each code was organized to create overarching themes, which were primarily based around the emotional responses of participants. Next, the relationships between the codes and themes were considered both horizontally, in terms of themes across data, and vertically, in terms of the temporal nature of how the stories unfolded. The decision to analyze the data vertically and horizontally was made during the analysis process, as it became apparent that there were distinct temporal stages. Such an

analysis strategy has been used by Braun and Clarke (2013), who identified the vertical patterns when exploring the story progression of a young woman ‘coming out’ to her parents as non-heterosexual, and Wadey et al. (2020) who considered how sport psychologists work with injured athletes to facilitate sport injury-related growth.

The analysis process was supplemented by the first and third authors, acting as critical friends, as well as challenging the second author on the development of themes. This process of investigator triangulation provided a theoretical sounding board to support reflection upon, and exploration of, multiple and alternative explanations and interpretations in relation to the analysis of data (Smith & McGannon, 2018). For example, four temporal themes were initially identified, but the critical friends felt an additional theme was needed to encapsulate the time in an athlete’s life when they were not affected by the symptoms of neurodegenerative disease. Thus, a further temporal theme was added, making five, that included: i) Before recognizing changes in behaviour; ii) Initial changes in behaviour; iii) Severe changes in behaviour; iv) Life after death; and v) Moving forward. In terms of the horizontal themes, the codes that referred to demands, challenges, emotional responses, and how the participant coped with each situation, were then organized against the five vertical themes to represent the participants’ experiences across these five stages. A summary of the analysis can be seen in the tables in the supplementary files.

Following this thematic analysis, Creative Analytical Processes (CAP) were used to present our results in an innovative and thought-provoking manner. Such an approach allows vivid emotions and images to be conveyed (Sparkes & Smith, 2014), and offers the reader opportunities to learn and critically reflect upon real-life issues built on a research informed knowledge base (Fenge, Jones, & Gibson, 2018). Specifically, we developed an ethnodrama (a written CAP in the form of a play script), to produce a fictitious conversation based on our data. Prior to commencing our writing of the ethnodrama, three characters were created (two partners, one child) by combining similar personality traits demonstrated by the participants to ensure they all had representation.

Developing composite characters also served to protect the identity of the individual participants (Smith et al., 2015). All of the relevant quotes related to each theme were recorded in an excel file, to facilitate writing the scenes. The five temporal themes from the vertical analysis provided a skeleton framework for the dialogue, with a scene developed for each temporal theme. Key sections from the data were extracted and merged together through a creative writing process to create a coherent and compelling dialogue, with direct quotes used as much as possible to best preserve the participants' voices.

Dowling (2012) suggests that an appropriate plot needs to be developed to link incidents together and thus, we set the dialogue in appropriate contexts where the characters would discuss their family member. Specifically, we set the conversations in different 'locations'; Scenes 1 and 2 were in a workshop at 'The Huddle', with the scenario of being asked to reflect on their family member before the neurodegenerative disease was seen to affect them, and then when they started to notice a behavioral change. Scene 3 was at the hotel bar, where they discussed the more severe behavioral changes. Scene 4 was again framed as a workshop discussion; and Scene 5 was an online conversation held between the characters a week after the event. Various criteria might be used by readers to make judgements on the presentation of data in this study, based on the guidelines of Sparkes and Douglas (2007). For example, does the ethnodrama provide the reader with a meaningful picture of the lived experiences of the participants? Is the dialogue plausible in the way different perspectives are represented? From a practical perspective, is the dialogue readable and accessible to different audiences? Readers are invited to approach the following dialogue with such questions in mind. For instance, for those who may be affected by similar situations of a family member suffering due to neurodegenerative disease following sport participation, does the dialogue resonate with their experiences, does it invite dialogue and reflection, and is awareness raised about the emotional responses of participants in this context?

## **Results**

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## Scene 1: Before Recognizing Changes in Behavior

*It's 9am on Thursday morning, 'The Huddle' has begun, and guests are coming in, going up to the desk to sign in ready for the workshops to start. Helen walks into one of the workshop rooms where Noah is already standing by one of the tables. Feeling a bit more confident, as it is her second time attending this conference, she walks over to Noah.*

Helen: Hey, I hope you don't mind me introducing myself! My name's Helen.

Noah: Hi, I'm Noah, nice to meet you. I've never been to one of these before, I'm a bit nervous.

Helen: Ah, don't worry, I came last year. Stick with me.

*(Then Sarah walks in and looks around for a place to sit)*

Helen: Hey! Would you like to join us?

*(Sarah smiles and walks over to where Helen and Noah are standing)*

Sarah: Hey! Thanks for calling me over, I felt like a right loner. I'm Sarah by the way.

Helen: Hi, I'm Helen. This is Noah.

Noah: Hi Sarah.

Helen: Why don't us three stick together today.

*(Noah and Sarah nod in agreement, and the three of them sit down at the nearby table)*

Helen: So, obviously, we're here for all the same reason. Who was affected in your families?

Noah: My dad had CTE<sup>1</sup>.

Sarah: It was my husband.

Helen: My husband too! It's such an awful disease isn't it. Tell us about your husband, Sarah.

Sarah: Thanks! Yeah, he was a gifted athlete, just so natural when he was young. He played basketball, football, track. But football was his love. He excelled at it and was a varsity starter when he was a freshman in high school, the best on the team.

How about your husband Helen?

Helen: We were high school sweethearts. I'd known him since we were 15 years old. I just loved him so much. He had the biggest smile, heart of gold. Kind, always supportive of me. And the life

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<sup>1</sup> CTE or Chronic Traumatic Encephalopathy is a neurodegenerative disease similar to Alzheimer's disease that has been associated with repetitive head impacts in contexts like sport and the military.

of the party. Everyone loved him. He made everybody feel so special, and he was full of love. I was proud he was my husband.

Sarah: How about your dad, Noah?

Noah: To be honest, I don't have such positive memories of my dad. I remember my mum would call his secretary, who would warn my mum of his mood when he left the office. He was very controlling. Nobody could be on the phone or in front of the TV when he got home. We just thought that was the way families were. He was a cold man with respect to his family, but he was very warm and engaging in public.

*(Sarah nods in agreement)*

Helen: Yeah, it wasn't all happy for us either. Early in our marriage, he was always getting speeding tickets. Always doing dumb things, always taking chances, but he never seemed to get hurt. I guess I just accepted that was him. It wasn't easy, even before he started to decline.

Noah: I feel bad for saying he was like that because I don't want to remember him that way, but at the same time, I can't change what he was like before he got ill. I remember my oldest brother came home one day and told my dad he was no longer playing football. It's one of the most gruesome memories I have. I mean, when my dad heard that, he just beat the living daylights out of my brother. He was a huge man, and could be violent towards my mum, so looking back I don't have the best of memories.

*(Sarah and Helen's eyes widen in shock)*

Helen: Oh, I'm so sorry Noah. That must have been really awful. My husband played aggressively, he knocked the snot out of people. But he'd also be the one that helped them up. He wasn't aggressive at home, he was actually a genuine, soft, loving person... A big teddy bear deep down. Everybody loved him. Great sense of humor. He had a larger than life personality.

Sarah: It's hard when you don't have the best of memories of that person. Yes, my husband and I had our difficulties, but we were always very much in love.

Helen: I guess that's what makes it harder when things do start to change. What sport did your Dad play, Noah?

Noah: It was [American] football. Apparently, at age five he'd play with middle schoolers, and that's all he wanted to do. He was constantly playing, and he had 30 invitations for colleges because of football. But he was very strong in track and field, and in wrestling. In that aspect, I am proud that my dad was such an incredible athlete.

*(Sarah and Helen smile at Noah)*

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Sarah: My husband played pretty heavily through high school, and the stories that I heard from him, you know, he talked about playing with injuries. He would have maybe a broken arm and they would just put it in a cast and he would play with the cast on. That can't be right! I remember he even said that he had been admitted to the hospital and was fed intravenously to help beef him up. Looking back, its mad the level coaches want their athletes to go to!

Helen: My story is similar in this respect. My husband was an all or nothing type person, a ski racer when he was younger. He started playing tackle football at the age of six, and then later, lacrosse. He was so good at all his sports, but in high school, they said 'you cannot play college football because you've had too many concussions'. He played lacrosse, but even then, he got a bunch more concussions.

*(Helen pauses, and Sarah and Noah wait for her to continue)*

Helen: It's really nice to actually talk about this, you know, before it went downhill. I feel like you spend more time talking about the bad stuff.

Sarah: Exactly! And it's great just to hear other people's stories that you can relate to!

*(Noah nods in agreement... at that moment, other people enter the room ready for the workshop to start)*

*Reflective Summary: this scene illustrates a little of the background of the three characters, their lives, and their loved one, before changes in behavior began to unfold. The scene shows how each character had different memories, with Helen remembering her husband with fondness, compared to Noah who had some negative memories. The scene finishes with the three characters appearing more comfortable with each other and ready and willing to share their experiences.*

## **Scene 2: Initial Changes in Behavior**

*The workshop begins, with the facilitator providing questions to encourage the delegates to discuss their experiences. Helen, Noah, and Sarah are sat together, already comfortable in sharing their experiences. The next prompt is offered: "So, remember back to when your family member's behavior started to change. Discuss in your groups your memories of this."*

Helen: I'm happy to start, if you don't mind?

*(Noah and Sarah smile and nod at Helen)*

Helen: So, for me, my husband and I were always very attracted to each other and very much in love. Then, he started creating some distance. I was convinced he must be having an affair. He was using pornography, claiming that it was stress relief. I couldn't understand what had changed. Like, why is he being like this? It just felt like our whole world turned upside down, yet I had no idea why.

*(Sarah's eyes widen)*

Sarah: I felt exactly the same! My husband just became disinterested in everything, including me. It was so confusing. You just question yourself like, is it me? What have I done wrong? Especially when everything has been good for so many years.

Helen: I know... it was just horrible. I felt like I was losing him. We went to marriage counselling, and I really thought it would work. At that point, I couldn't hide it anymore, and I had to tell our eldest daughter. He couldn't cope with emotions and stuff, so it was hard to hide.

Sarah: The emotion thing was so crazy for me too. My husband really couldn't manage any type of emotional regulation and couldn't even handle my emotions. Like, if I was upset, or if I was just tired, he took it personally. It was really hard to deal with, very draining.

*(Helen and Sarah nod in agreement, and look over to Noah)*

Noah: I was young, but I remember my mum saying his moods were all over the place, and he really couldn't take care of himself very well, and he didn't make good decisions. He started to be a lot less present, and tired, and we just thought 'what is going on'? So, I guess, like what you said. Just confusion and worry.

Sarah: Confusion is the word! He started to spend money like crazy. Like, one time it got to \$20,000 in three months, and at the same time, he wasn't paying our bills. He'd buy high volumes of stuff like paper towels. Crazy stuff, teeth whitener, or tires that didn't fit the car. I mean, it was seriously frustrating as he just kept doing it. It was so crazy, and I thought 'what are you doing'?

Noah: My dad's spending was a real worry too. Impulse purchases, not taking care of bills that he was always in charge of, which wasn't like him at all. He'd apparently always been very careful with money. This took a bad toll on the family.

*(Sarah and Noah nod in agreement)*

Sarah: I mean for us, the impulsiveness with the money was scary. He was the only breadwinner in the family. I'd been a stay at home mum, ever since the kids were born, and so no ties to the working world and very low earning potential if he wasn't earning money. Stressed doesn't even cut it! I was a bundle of anxiety.

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Noah: I could see the stress on my mum's face too. He wrecked a car. You know it's just one thing after another he was doing, with this crazy behavior, and I kept saying "what is going on?"

Helen: Not sure if you both experienced this too, but memory loss definitely started to creep up on him as well. Like, I remember once we sent him shopping. He came home with all the wrong stuff. I was kind of like "that's weird, why has he done that?"

Sarah: Yes, the memory did just decline, I started noticing little things, like we had a second home in the mountains, and he went up there to close it up for the winter. I went back up there for a couple of days and he hadn't emptied anything out of the fridge... fish, food, he had just walked out and left it, and turned all the electric off. It was like his memory had just gone. He went from functioning perfectly, to struggling to remember or do anything he was so used to doing. I felt lost and a bit hopeless if I'm honest

Helen: It was very similar for us! I remember once when he went to the airport to pick up my aunt. He proceeded to drive her around, and she finally said, 'where are we going?' He said, 'I don't know'. He just lost that processing for himself which made me super worried.

*(Noah nods his head in agreement)*

Noah: I remember that became a real problem for my dad too. When he went to the grocery store, it's not just that he wouldn't know what to pick up, he wouldn't even know that he had to take his wallet.

Sarah: It's crazy really. Looking back, the changes were quick and out of the blue, and I think I was a bit naive about it all at the start, but I guess I didn't know what was happening either.

Helen: I do think at the start you are in this sense of disbelief because the person you love is doing these things that are out of character.

Sarah: The memory loss got quite scary for us too, because my husband was allergic to nuts. He also loved garlic, and one day one of our friends gave him garlic-flavored nuts. And he nearly went into anaphylactic shock and died. Now that was seriously confusing and worrying. The memory loss meant if we went out to eat, he would forget to tell the staff he had the allergy so just ate the food even though it made him ill. That panicked me.

Helen: That must have been so difficult for you.

*(Noah nods, agreeing with Helen)*

Noah: My dad just lost interest in my life a bit. I know that sounds horrible. He would take me to practices, but then, he just lost interest. That hit me hard emotionally. I think that has caused me to be a bit isolated sometimes as I just got used to being by myself and my dad not really caring.

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Sarah: And trying to communicate that to other people when you didn't understand yourself what was happening. I felt so confused, lost and overwhelmed by the situation, it was so new and so odd, I felt stuck.

Noah: My dad lost all his friends because of his disinterest. He lost everything. That's when he divorced my mum, which was kind of unexpected. It was a decision that nobody understood, and even to this day, I still can't get my head around that one.

Helen: The hardest bit for me, emotionally, was when he broke down and kind of said: 'I'm really struggling with depression'. I was shocked, but also felt like the world had been turned upside down. We were so happy. I remember just sobbing, but I guess I was lucky he didn't become suicidal. I remember someone else I was talking to last year saying that their husband said to her, 'I don't know what's happening to me, but I'm pulling over to the side of the road... I want to kill myself'. I felt broken just from my husband telling me about the depression, I couldn't imagine what that lady went through.

Sarah: I know a lot of the changes are mental, but did either of you notice any physical changes? Like, being an athlete, he's always been so fit and healthy, and I remember once he was carrying a big drawer that was full of stuff and he tripped over and fell down.

Helen: That happened to my partner! It's like his coordination went, and he kind of stooped over and he would shuffle all the time.

Noah: I didn't really see much physical change at the start. For me, I noticed more like language problems, he was flipping words, then forgetting, and he struggled to communicate.

Sarah: I think it's so difficult to understand it if you haven't gone through it yourself.

Helen: And this was just the start. I don't know about you, but it got a lot worse from there.

Noah: I don't really talk about it often, I find it difficult, but it's nice when people understand.

*At that moment, the workshop facilitator asks them to wrap-up their conversations, ready to feedback thoughts to the rest of the group.*

Sarah: *(whispering quietly to Noah and Helen)* I'd love to chat again, to hear more about your stories. I think it's going to be helpful to talk all this through. Let's meet later.

*(Helen and Noah nod in agreement. The facilitator talks in the background and the scene ends).*

*Reflective Summary: the prominent emotion displayed by each of the characters within this scene is confusion. The conversation illustrates how the initial changes in their loved ones' behavior caused*

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*them to question themselves and their relationships. Unreliable spending habits, erratic moods, and poor memory of the athlete made the family members feel they were “losing” their loved one. Comments such as “what have I done wrong?” show how the family members questioned their own response to how they dealt with these initial changes, which added to their sense of uncertainty about the potential impacts of such behavior going forward. Nevertheless, the scene ends with the characters feeling positive about talking this through with others who have had similar experience, and showing a desire to continue their conversation later.*

### **Scene 3 - Severe Changes in Behavior**

*After a long day at ‘The Huddle’, Helen, Sarah and Noah had agreed to meet at the lounge bar at 8:30pm. Sarah arrives first and sits at a table. Soon after, Helen and Noah join her. They order drinks, and resume chatting.*

Helen: It was so nice talking to you both earlier!

Noah: It was great! I felt a bit relieved after we spoke about it all, I think it’s because it was the first time I’ve actually spoken to someone else about it.

Sarah: I really enjoyed it too! Where did we leave off?

Noah: I think I was talking about the language problems.

Helen: Ah yes, that was it! So, I guess we realized that the early signs were the things like memory loss, loss of communication, and struggles with mobility.

Sarah: Exactly! So, when did you realize things were starting to get worse?

Helen: Hmmm, he lost things, like our taxes. One day, he was supposed to take them to the accountant. He put them on the top of his car, drove off, and they blew all over the county. Also, he didn't even remember that I gave them to him.

Sarah: My husband’s memory just progressively got worse, and it impacted on how he was with us. I’ll give you an example. On his birthday, our oldest daughter gave him a gift that he always asked for, a t-shirt with some funny saying on it. My daughter had it made for him, and when he opened it up, he just looked at it and either didn't catch the humor, didn't remember, or didn't care. He just didn't respond.

Helen: That must have been so frustrating! I remember once he let the dogs out one night and didn't let them back in, but I didn't realize, and at like three o'clock in the morning, the police come to our

house saying there's been complaints about dogs barking. I couldn't believe that he had forgotten to do something so simple.

Helen: He was also spending massive amounts of money. When I asked him what he was spending it on, he never gave me an answer, I just constantly thought he was lying to me. So, I was ready to leave, I was fed up, but his sister talked me out of it.

Sarah: For us, the memory had gone too. One weekend, I had 12 big black trash bags to go out to the garbage. And I told him when I got up and went to work on Monday morning, I said, 'those are going out to the trash tomorrow'. I came home after work and he had unpacked every trash bag... I just sat there and cried... I'd worked a 12-hour day. I said, 'why did you unpack all that trash?' and he couldn't tell me why, he just didn't know. I was so drained.

Helen: It was like my husband just lost focus and became incapable of daily tasks. It wasn't nice to see... He just, he wasn't functioning, it was heartbreaking.

*(Sarah and Noah nod, realizing they completely relate)*

Sarah: I wish I would have been just gentle in my response. I wish I had just said 'come on, let's put your feet up and let me massage your back', you know.

Helen: It's hard because you don't know what's happening. So you just blame yourself and think you are the reason. And that's not good for your own wellbeing.

Sarah: Were there any other changes you both saw?

Noah: My dad began gaining weight as well, he stopped working out, and he'd always worked out. He began isolating himself.

Sarah: *(nodding in agreement)*. Yeah, my husband was getting big too! He was going to Overeaters Anonymous and they told him he was an alcoholic. So, he started going to AA [Alcoholics Anonymous]. It just was one thing after another.

Helen: Same with my husband too. He was always meticulous about how he groomed himself, always clean. But he just lost that crispness that he had, you know, and he was really struggling with his weight all the time.

Noah: My dad too! He grew his hair out. He had this long ponytail, which was bizarre. He didn't dress well anymore. I began Googling, trying to figure out what's wrong with him. He was drinking heavily, and his behavior was erratic. He was angry all the time, even more than usual which was scary.

Sarah: I was so angry at him for making the same choices over and over with drinking though. Like, 'you've drank so much that you fell down the stairs in front of me at home, are you kidding me?' And it hurt, you know, and left a lot on my plate, so I was really, really, angry. And that didn't help things.

*Sarah pauses...*

Once, he even held a gun to his head and I thought, this is it. But he talked himself out of it and later said it wasn't something that he was thinking about doing.

*(Helen and Noah looked shocked)*

Helen: Gosh, that must have been so frightening! It's weird how erratic their behaviors could be! I couldn't physically handle him either. At that point he was unstable. He would shuffle, and fall, and he couldn't get in and out of the shower. He was also incontinent, and I couldn't handle him by myself. I felt so weak.

*(Helen and Noah sit back, waiting for Helen to continue).*

And plus, he was getting out at night. I didn't know where he was going. He was having hallucinations, he thought that one night he was out feeding the homeless, but he was in the driveway in his underwear. Another night he thought a space shuttle was landing in the garden. I was so tired, so physically and mentally exhausted. It was just like my life was over too.

Noah: My dad would hallucinate as well. He would see things out the back window, and say something like, 'do you see that turtle out there?' And I'm like, 'no, there's no turtle'. Or police officers would show up because he couldn't figure out how to get back home.

Sarah: It's just mad thinking about it isn't it, like, anyone who hasn't experienced this would just be like 'what?' So, it's nice talking to you guys! But yes, the same with my husband, he would wake up in the middle of the night, and he would talk about seeing dogs or people in the apartment. I wasn't really prepared or knowledgeable about it.

Helen: Yeah, you then question your own head too!

Sarah: And then the mobility goes, continence, his speech. He could still talk to us, but it was in much shorter sentences. It wasn't like a conversation. It was a few words.

Noah: It was just like one thing after the other, wasn't it? Dad really kind of deteriorated and then started having lots of falls.

Sarah: You're just constantly running around, making sure they don't put a foot wrong or don't get in danger. It's draining! He started getting these tremors in his legs too, and that's when his

communication skills were getting worse because he couldn't explain that his legs were bothering him. He'd also get up in the middle of night and go to the toilet, but not in the bathroom, it was almost like he was sleepwalking. But he wasn't. He'd go pee in the closet or something.

Noah: All control just went didn't it! My mum and I noticed that his behaviors started getting worse, including at social events, which was difficult.

Helen: Oh yes! I remember he was thirsty one time at a party and took the faucet that comes out of the spray nozzle and just sprayed water into his mouth in the middle of this kitchen in a multimillion-dollar house. And then you suddenly start losing your friends.

Noah: It's so hard! When we went to events, a lot of people thought he was an alcoholic, because he could have one cocktail and then he'd fall. They had no idea that the falling had nothing to do with that one drink that he had. And it became very sad because people didn't want to have us around.

*(Sarah nods in agreement)*

Sarah: That happened to us too. We went to a catered event and he would take the top of the bun off, take the meat out to eat, put the bun back, and then go to the next one. And someone caught him and was like, 'what is he doing?' Of course, we never got invited back to any of those people's homes. No one wanted to have anything to do with him because they couldn't understand him.

Helen: Exactly! It was frustrating. When we got him some proper care, they didn't understand the pattern of his behaviors. He wasn't sequencing. They'd take him to the restroom, say 'press the red button when you're done'. He'd get in there, he'd be done and then he never pressed the button, just stood there waiting for someone, you know. So, there were all of those little things that the medical community didn't pick up on.

Noah: Same with my dad. Like, he couldn't communicate how much pain he was in even though you knew the pain was horrific, but because he didn't say anything, they didn't give him medication. Medical staff really need to think creatively about how to manage that with someone who's cognitively impaired.

Helen: And then, of course, as anybody here will probably tell you, the sheer problem with these guys was their physical size. As the disease progressed, he fell probably 10-15 times a day, and we'd have to figure out how to get him up. I was both physically and mentally exhausted.

Sarah: It made me ill as well. Once, I called my doctor's office, and I was in the hospital for five days, and then had to go back for various surgeries. I'd allowed it to get so bad - I was completely oblivious to my own needs because I was caring for him. It made me even more stressed as I needed to look after myself and my husband, but I couldn't.

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Helen: Poor you! It's just so incredibly stressful. I remember when we went to our New Year's Eve party. I remember applying makeup twice just from crying, as the fighting had escalated. I felt dejected and just hopeless. Like, what was happening? He just constantly looked so disturbed and annoyed, and it wasn't the man that I knew. It was just bizarre and... and I would just beg him to be nice to me. Just please can you just be nice to me today.

Noah: My dad's temper started picking up too, I think it was to do with the fact that he couldn't articulate or express himself anymore. That was so hard, then when he started lashing out, you know. It was just really tough. The hardest days.

Sarah: I remember the start of my husband's temper change too. I really wanted to take my son to Disneyland. My husband just said he didn't have the time. And I remember thinking 'this is so strange'. I mean, this is the man that would do anything in the world for our family, you know. And this was the cruelty that came out, when he came home one day, and he says, 'I'm taking him to Disneyland with my fraternity brother'... and then he says to me 'you're not coming'. I was so depressed by it all. I actually called the psychologist and I just wanted to kill myself, it was that bad. I just said, 'I can't keep living like this'.

Helen: Oh, how awful! Because my husband was declining, and I couldn't physically manage the falls and stuff, we put him in a medical center for help, and the aggression kind of showed up more then. So that was stressful because we would get calls all the time that you know, he's done this or he's pushed a chair over, he pushed one of the caregivers or whatever... It was hard. As that stuff started to shift, that's when I just knew I had lost him.

Sarah: I did become scared of him. I hate to say that, but I did. He made me sign some papers and I had no idea what they were. He was just escalating and escalating, and he was standing over me and I just knew if I didn't sign that paper, I was in physical danger. Which was an awful thought to have about your own husband that you love. It's so hard because you are trying to deal with the aggression, and the fact that he has lost his identity, and his personality is just not the same as the one you knew and loved.

Noah: Exactly! It's just like so back and forth emotion-wise. One minute you feel sorrow for them and the next is like "what the hell have I done wrong, I'm just trying to help you!" I remember we were at my family's house when my dad just completely ignites and attacks my wife and myself verbally, saying that we're poor parents, just very maliciously in front of this whole crowd of guests. And in those moments, it's so hard to feel sympathy for him and rationalize his behaviors.

Helen: Wow! Now that just sums up how mad this disease is. I can't imagine how difficult that was for you! I was lucky my husband never got to that extent.

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Noah: I mean the rage just continued until he got to the point where he was unable to do anything you know; he was like a caged animal. I didn't even know who my dad was. This disease just completely robbed us of my father.

Helen: Exactly, it does just rob you of the person you love. Emotions just go from one end of the spectrum, like feeling grief, to the other, like feeling such anger.

Sarah: Like I said, I had never in my life been afraid of this man. He was most calm, self-controlled, just the gentlest man. And I became afraid of him. I know there was a point where I was on the phone with my oldest daughter, and he was tearing around the house. Sometimes, we had to call the police. We didn't know what else to do really, one time we called them because he threatened suicide through a text.

Noah: It's like your world is just turned upside down and you just have no control. It was a lot of frustration of why is he doing this? Why is he behaving like this? And really, those few years of trying to find the answer, which my mum and I look back and are like, "those were pretty bad years".

Helen: It is so frustrating, but then you have to remember how frustrating it is for them too. Like my husband, he was a brilliant man and very gifted in many ways. He had the gift of the gab, this man could command a room. And then, you know, he just lost every gift he had.

Sarah: That is a good way to put it! He was strong. He was the rock always, you know, it was just... The best husband, the best dad, he was all of it. He lost every gift and that was the saddest part. Eventually, he reached a point where he couldn't really talk. He was pretty much non-communicative.

Helen: Same! He was just apathetic, depressed, negative, saying very inappropriate things. Again, just very erratic behavior. But ultimately, it progressed into where he lost interest in all the things that he used to... all of the things that would bring him happiness during the day. He used to speak to his college friends all of the time, and we found he had stopped. He wasn't getting any satisfaction out of anything.

Sarah: One day, I went to lunch with friends and I really had a good time and I would feel guilty. And then I would think, but he's warm and he's dry and he's well fed, and I'm doing all I can do for him.

Noah: Same with my dad too. I could just look at him and tell, he just had a different look on his face because he had failed so much. It was heartbreaking. In the last two years of his life he didn't walk, and he didn't talk at all. It's hard to come in and see your dad like that. You're like, "man, this

is just not dad. This isn't the guy who raised me. This is not even the shell of the man he was". It was heart-breaking.

Helen: You're just watching somebody you love disappear before your eyes and it's hell.

Noah: Exactly! Like at the end my dad was drooling and wearing diapers, like no one should have to see that. I was a wreck. That's why I haven't really told anyone until now.

Helen: I think this disease just slowly kills the both of you.

*(Noah and Sarah not in agreement)*

Noah: It's so draining to even talk about now.

Sarah: It really is, I don't know whether I need another drink or to go to bed!

*(Noah and Helen both chuckle)*

Helen: We do have another busy day tomorrow! The huddle is amazing, but it is full on!

Noah: That's true. I might head off then, and get a good night sleep before the morning.

Sarah: Sounds like a good plan to me.

*(They all finish their drinks and get up to head back to their rooms).*

*Reflective Summary: key emotions of confusion, shock, and despair were prevalent throughout this scene. The characters expressed a sense of disbelief with the behavioral changes becoming more frequent. Furthermore, this scene illustrates the consequences of these changes on the family members of the athlete. Specifically, Helen describes her heartbreak and mental exhaustion, and Noah expresses how his life became extremely sad and isolating as his father's behavior was so bad that others didn't want to be around him. A lack of understanding about what was happening really accelerated feelings of frustration and helplessness, although confusion lessened as the family members were beginning to understand the athletes' patterns of behavior. However, the characters also recalled how speaking to health professionals who didn't understand the athletes' condition subsequently intensified their feelings of worry. The scene finishes with the characters feeling a sense of sadness from discussing these severe issues, as well as feeling drained from the conversation.*

#### **Scene 4: Life After Death**

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*A new day, another workshop, and the facilitator starts by saying, “welcome back everyone. In this session, if everyone is comfortable, we want you to discuss what happened after your loved one passed away’.*

*Helen, Sarah and Noah are sitting together again, and they start up their conversation very easily.*

Helen: This part is obviously a lot harder to talk about, so take your time! I’ve been to this conference before, so I’m used to talking about this.

Noah: Don’t worry, I’m just going to go straight into it, so I don’t psych myself out from talking about it. Well, my dad just continued to decline and was in and out of hospital. That time was really tough, it was just like watching someone you love disappear in front of you. And I remember when the psychotherapists said, ‘you have to make a decision, you need to decide what you want to do because this could go on for the rest of your life. He just doesn't care’. Being told your dad doesn’t care about you anymore? Well that was life wrecking. You just feel confused, sorrow, isolated, such a range of emotions, it’s horrible. But he wasn’t the man I knew. Anyway, by this time his liver had shut down, his kidneys were shutting down, and he passed away, traumatically, from that.

Sarah: My husband’s body just shut down too. He broke his right femur to the point that he had to have surgery, and plates and screws put in the femur. Being a big man, that was a big surgery. He then became addicted to pain meds and just was such a mess, and I couldn’t risk him being at my home, or near my children at this point. One night we talked on the phone, and at the end, he said ‘I love you’, and I said, ‘I love you too’. That’s the last time we talked. That night he ended up accidentally overdosing.

Helen: That must have been really difficult for you both. Hearing others’ stories definitely demonstrates the different effects this disease has on people. We had my husband in a hospice, so we were lucky, and it was a very peaceful death. I knew it was coming, I saw it coming the week before, his whole demeanor changed. Every day that I left him, I told him that I loved him because I didn't know if I'd see him the next day. It’s heartbreaking as you know what’s happening, but you don’t want to believe it’s true.

Sarah: I lost a ton of weight because I was so nauseated by the fact that I thought I could have done something more, I don't know, like I thought it was my fault?

Noah: But I feel the same, there’s so much guilt, like I should have done something.

Helen: You have to remind yourself sometimes of how much you did do to help your husband and your dad! It is easy to blame yourself but what good is that doing to you.

Noah: It hit all my family differently because we all had different relationships with him. When he died, it was such a sadness for me, like I was sobbing at home, and going through the natural grieving process.

Sarah: For our first nine months, the kids wouldn't let me go into another room without being next to them. They slept in my bed, they needed a sense of safety and security, you know? But my oldest definitely was affected more as he had more understanding at the time, and it was hard to deal with that whilst going through the grieving process myself, it was draining.

Helen: That's what is difficult about giving advice to others, the effects of grief are so individualistic. That's why it's just good for us to share our stories. But when you don't know the cause, the only thing to really blame is yourself and I think that's what the problem is.

*(Sarah and Noah nod in agreement)*

Noah: So true. It's not until they're gone, and you look back at what you went through. Like, you slap a band-aid on it because you just have to keep going and then when they pass away, it's like all those band aids get ripped off. And that's when you have to heal. And that's where you have to take a step back and process everything.

*(Helen nods and smiles at Noah)*

Helen: I agree Noah, you don't have time to grieve the loss, because you're in the throes of just keeping him safe, and keeping him happy, and keeping him clean, and well cared for. You're advocating for him. At the end it's just the importance of being with them, you know, just being there and present.

*(Sarah looks down into her lap, Helen grabs her hand as she notices she's getting upset)*

Sarah: That's why I think I have found it so hard, as I wasn't with my husband when he died, I wasn't there to comfort him. I just wish I could go sit and hold his hand, you know, like, I wish we could just sit and hold hands, just for me to let him know, I'm there. I think anyone who has lost someone knows this, but the sadness you feel is just indescribable. I have come a long way since the initial guilt and stuff, but I do regret not being more vocal with how much he impacted my life. I wish I could tell him how much he meant to me.

Helen: It sounds bad, but I was relieved in a way. For the kids, they have this dad that sometimes presents himself as amazing and awesome but then can't follow through. His drinking was also getting to the point where I couldn't manage it anymore. And I don't know how that would have played itself out. It's made me realize I'm just happy he didn't hurt anybody else, like me or the kids in any way. It could have been so much worse.

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Sarah: I couldn't agree more. It's so easy to make yourself ill as well, and looking back now I risked my kids losing both of us because I wasn't looking after myself too.

Helen: I don't know about you, but I also had a lot of information to pass on to the researchers at Boston when we were doing the research portion of the autopsy. I wanted to get the answers. Anyway, because of that, we got the diagnosis pretty soon after he passed away. It was like a light at the end of the tunnel, it was relief. It was like, okay, there was something wrong. We're not making this up. I think getting the diagnosis justified everything and no it didn't make the grieving process easier, but it did mean that we didn't blame ourselves, as we had no control over it.

Sarah: Yeah, that was the same for us. When we found out it was stage three/four CTE, I was devastated because I thought, "oh my god, he was so sick". And here we were sort of punishing him to try to get him to sort out the drink issue but I feel so guilty as it was the CTE not him. But like you said, it made it that slightest bit easier as you had this sense of understanding.

Noah: We didn't get the diagnosis straight away. To be honest, I had never heard of CTE. So we didn't have the benefit of knowing that this was the issue and that it's impacting athletes. We didn't know of any other athletes that were struggling with similar symptoms and so we were very blind in what we were dealing with and not really understanding what was going on. I think that made the grieving process even harder as you're just constantly questioning yourself.

Honestly, I was nervous about coming to this event, because I struggled with grief so intensely last year, like throughout the whole year. It has been a bit of a relief to get it off my chest here.

Helen: Being here has helped me so much, that's why I keep coming! Everyone here is in the same boat. It may not have looked exactly the same for us, but we don't have to explain for once. And just the support I've got from the people here has been great.

*(The facilitator signals the discussion is coming to a close)*

Sarah: I agree with you, I will definitely come again, particularly for the support and to talk to people like you both.

*(Helen and Noah nod in agreement)*

*Reflective Summary: this scene revealed negative emotions such as sadness and distress in the family members as the athletes passed away. Even though the family members were generally prepared for death (e.g., Helen saying "I knew it was coming"), guilt was an overriding emotion, and they felt they should have done more to help. However, as the conversation became more reflective, the overriding emotion experienced changed to one of relief, as they no longer had to go*

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*through such draining and challenging situations. This relief also came about through diagnosis after death, with the knowledge that the athlete actually had a neurological disease, which provided an explanation for their extreme changes in behavior in the last years of their life. The scene finishes with the characters feeling positive about sharing their stories, and how this opportunity to talk about their experiences made them feel supported.*

### **Scene 5: Moving Forward**

*It's been 2 weeks since the conference. Helen, Noah and Sarah have arranged an online video call. As their faces each appear on the screen, they all smile broadly.*

Helen: Hi guys, how are you both?

*After some small talk, they start discussing their personal reflections from the conference.*

Helen: It was so lovely to meet you both the other week at the Huddle and talk with you. It's easy to say this but I really don't think anyone understands what we've gone through unless they've gone through it themselves.

*(Noah and Sarah nod in agreement)*

Sarah: I agree. The Huddle was great, but it's also stirred up such a mix of emotions. Like, I am so devastated about what this illness did to our family but also I have huge guilt, because I look back and just think he suffered unnecessarily, because we didn't really know what was wrong with him. My kids also had this disrespect for their father because he was so horrible to me.

Helen: As much as I've struggled, I realize I've got a lot to be thankful for. I'm thankful for the diagnosis and thankful for all the research that's happening that we heard about at the Huddle. I also feel grateful as our story seems like a fairytale compared to others – I've heard some horrendous stories of what happened to other wives.

Sarah: That's what's good about hearing other stories, you can appreciate the better parts of yours! That being said, there needs to be more knowledge. Like, the risks need to be known, and healing protocols need to be developed. And you know, so if you do get a head injury, you've reached this new level of possibilities of bad things happening.

Helen: So, I think education is always key, just educating people. And I'm outspoken about it, like, if people say, 'oh, what did he die of?' I don't just say, 'oh, it was, you know, CTE'. They'll wish they hadn't asked... but I go into it saying it's a traumatic brain injury related to football - it's a disease that basically ate up his brain over the course of many years. And when you put it that way, they're shocked.

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Noah: Definitely. Talking about it and raising awareness can also bring healing. It helps even to have someone who knows what it's like to go through it. Just to have someone mail you a card and say, "hey, just thinking about you today". Having kind of a pen pal, mentor or sounding board, you know, to give you support through this. It's so important we help provide that.

Sarah: Yeah, that would really help! It was also good to hear the research behind it, to hear what they're doing at the Huddle. I've been thinking the key is prevention. Like, what are we doing to prevent this? You know, we don't have a treatment or cure. So, prevention's our best hope and so hearing what those people are doing with the research side of that, is great.

Noah: Yeah, we need to make sure other people don't have to go through this.

Sarah: I also realize looking back on what I went through that I should have taken more time for myself, as now I know how much damage the disease does to someone with it, but also to the people around them caring for them. If we were currently talking to people going through it right now, the biggest thing I'd say is get into therapy, to help you process everything and to let you have an outlet.

Helen: I agree, you've got to try and take some time for yourself. I remember I took a trip with a girlfriend once and I was scared to death the whole time I was gone, but I went, and we had a wonderful time, and I'm so glad I did it. You know, trying to keep some semblance of normalcy in your life for yourself, for your own good. Try to keep yourself healthy, eat healthily, work out. Keep yourself well because there really was nothing I could do for him except be present. I couldn't make him well.

Sarah: Yeah, my regret is perhaps I should have listened to my own needs. Because it almost killed me too. My children almost lost both of us.

Noah: Like, looking back, it's just horrible as we all suffered, our family broke up, and my sister's estranged from the family. It all goes back to my dad not being able to adequately provide and protect his family, which was frustrating, but now we realize that wasn't his fault, so like could all of that have been prevented? Probably!

Sarah: To look back now, you realize that there were the significant pathologies that he had no control over that were really affecting his decision-making capability. In one presentation at the Huddle, they talked about that region of the brain that's responsible for decision-making that erodes. His brain was still functioning, and he was still able to make decisions, just the wrong parts of the brain were directing his decisions. That totally makes sense now, so that's been a huge relief, that he wasn't just an asshole in his own right, he really just couldn't control it.

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Helen: I'm just very grateful to see some positive outcomes from this research going on. I think it makes my loss bearable. Because, you know, millions are going to benefit from this and hopefully not have to experience the kind of tragedy that affected our family. I know this may sound strange but it's interesting that my husband had CTE, I feel like part of the reason this happened is for me to be part of raising more awareness and be a part of this movement towards new culture change. I can help families navigate, you know, the difficult waters of dealing with this. And so I feel like it speaks to sort of a calling maybe I have in life or part of my purpose.

Noah: And also, talking to people! Chatting to you both has given me such a sense of relief. Like, you connect with someone. And that was nice. Somebody else who knows what this is like and can properly understand.

Sarah: Having someone to talk to has helped me so much because they understand how isolating the disease is. And to know that you've got this network of people who now connect because we've all been through similar situations. It's very, very powerful.

*(Noah and Helen nod in agreement)*

Noah: Being at the Huddle was amazing for me. Everybody seemed super supportive and it helps me in my grieving, and I'm looking to kind of get more involved in the organization to create more support for families as the disease is so isolating. No support came from the NFL either! The NFL have been hell bent on denying that there was any connection. They didn't want to know about his diagnosis. They didn't want to talk to the researchers to learn about what they're finding, which I just found disgusting.

Sarah: I also think that finding your own answers is really important... to do your own research to find what you can connect to your own personal situation. That is really important for personal peace with yourself.

Noah: A diagnosis would have helped us so much too. Because then there is a potential explanation for what's happening, and it saddens me that my dad didn't have that insight. I think he really was tormented by his inability to be the person he wanted to be. So, if we had known what the problem was, we could have had support in working through and anticipating the situations that are going to be challenging and having a game plan on what we'll do.

Sarah: When I think about what would be helpful for families today, certainly it would have been helpful to understand that a diagnosis would have been beneficial, just so that he wasn't beating himself up quite so much... so we can work together to try to make it as manageable as possible.

Helen: Agreed. I would also say 'get to a neurologist. Get baselines. Find this organization'. There's a new help line that I think is amazing. We've got to raise awareness. It is the worst thing I have been through. If you have a concussion, you need to report it and take the time to recover. And just be careful going forward, you have a whole life to live. Sport isn't everything... So, our job now is getting the people that you have a sphere of influence on to listen to you, and then have them share with the next person.

Noah: I agree, like just sharing your story will help so much. And that has taken personal courage throughout the last year. Like, I'm willing to share the story versus years ago when I was more withdrawn. I know now we need to take this stance and make people aware. After leaving the Huddle it has made me feel a much more empowered.

Sarah: I actually did a little small gathering for people that wanted some answers about what happened and told them there is a connection between sport head injuries and this disease. It was hard at first, but it's a legacy for my husband which helped me so much. But I'm worried about the future dangers of sport.

Noah: Me too! Media, advertising and marketing people are going on about how safe the game is and how safe we're trying to keep the game, and it infuriates me because they aren't making it safer. So, my wish would be that that even as a young kid, every parent would have that black book where they would keep records of things that might later impact. But that's part of the education process.

Helen: Good idea! I'm just so concerned this horrible disease is hitting younger and younger people, yet no-one knows about it, I'm not saying I don't believe that we have to stop playing our sports completely. But giving people the information to be able to make the correct decision is super important.

Sarah: I totally agree! I think understanding that it is a real thing, and it can affect you in ways that you don't understand, and you won't be able to understand because your brain is injured. So, the people around you really need to be informed on what to look for. Because once you have had so many injuries to your brain, you really can't trust yourself.

Noah: That's a great way of putting it.

Helen: We need to help the families that are struggling with this, to give them some resource, anything to help them understand what they might be dealing with. It creates incredible dysfunction and chaos. You're trying to untangle it for the rest of your life, the emotional damage that's happened. So, the sooner you can understand that this is a disease, that information can really help

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any family deal with it, and then people can provide the kind of compassion that their loved one needs to get through it.

Sarah: Ultimately, people should realize how dangerous the game is. I remember we went to an athlete convention, and guys are wobbling around on canes, and they look decrepit and at, you know, still at a very young age. And you realize, there's a price to be paid for playing these games, and that's why there is high reward, it's high risk. My husband knew that he was weighing the risks and the rewards and was willing to sacrifice somewhat his physical health, but I could tell you, he had no idea, no idea at all about all the cognitive, mental and head-related consequences.

*(Noah and Helen nod in agreement)*

Noah: I even find watching sport quite difficult now. This year was my first year of having a Super Bowl party where I didn't watch the Super Bowl, because now I am just not supporting it. I have made a conscientious decision that I'm not going to watch somebody else's family have to go through this because I want the thrill of the game.

Helen: I actually still love the game. But I don't love the consequences of the game. If they made some changes maybe I'd watch, but it's not worth somebody later in life, it's not worth people committing suicide over the pain that they're in.

Noah: When my dad retired from football, I basically did too, I quit watching it and I was mad every game, because I could see the damage.

*(Sarah nods)*

Sarah: I also think as parents, we need to look at that and say, okay, we have to take a better look at what kinds of sports we're allowing our children to play and really paying attention to the degree to which the head can be impacted.

Helen: Agreed! Surely nothing would be worth the risk of just putting your brain in that position versus other sports that I feel like can also teach life lessons and, in a similar way, have the same effect, you know, on personal development, so my kids will be steered more towards other sports and away from football and when they ask why I can tell them about the legacy of their dad.

Noah: I agree! Athletes need to consider the long-term effects of sport. We live in societies where we idolize these athletes, even though they don't make good decisions and that's what's dangerous.

Helen: Sport is valued over health and that's the issue.

Sarah: I realize football played such an instrumental role in so many of me and my friends' lives, but we're making a more educated, more aware decision for our children and their wellbeing. I mean, bottom line, when you look at this disease, it is preventable, totally preventable.

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Noah: I've had mothers of children say this is making me rethink whether I'm going to let my kids play football, and that's what we want to hear, people actually making a conscious and informed decision.

Helen: I think the awareness will snowball and I mean hopefully it will save a lot of people the agony of going through what we have all been through.

Sarah: Exactly, and it's an outlet for us now! We can see something positive come from something that was so tragic, which makes such a difference.

Noah: I think let's just do all we can to not let anyone else have to go through this.

*(Helen yawns)*

Helen: Sorry guys, I am shattered! I didn't realize how late it was.

Sarah: Wow, that time went quickly! Time for bed methinks.

Noah: It has been so great talking to you both again tonight! I'd love to keep in touch.

Helen: We have the WhatsApp group now so if you ever want to talk about it just send a message and we can arrange something.

*(Noah smiles)*

Helen: On that note then, I'm going to head off! Night guys!

Noah: Night!

Sarah: Speak soon!

*(They all exit the videocall, shut their laptops and head off to bed)*

*Reflective Summary: this scene shows how family members channeled their emotions into education and raising awareness about head injuries in sport, which in turn acted as a coping strategy to deal with their grief and allow them to move forward with their lives. Although emotions of guilt, sadness, and anger were all still evident throughout the scene, the family members also show their gratitude for a diagnosis and the research that is now being done, with a particular sense of curiosity towards how ongoing research will help other families. The family members also had some regret in not listening to their own needs, with a recognition of self-care as being necessary to minimize negative effects on their own mental health and welfare during such challenging times, as well as a desire to use their own experiences to help others move forward. The dialogue finishes on a positive note, with family members feeling somewhat optimistic about the future, and how something good was coming out of what had been a primarily traumatic experience.*

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## Discussion

With this research, we aimed to examine the experiences of a range of family members who lived with a former athlete with neurodegenerative disease, focusing on the emotional responses of these family members, as well as the coping strategies they used in this situation. We also aimed to consider their responses over a period of time, while offering suggestions to help support other family members who may be going /go through similar experiences. Finally, we aimed to present our findings in a novel way, using creative non-fiction techniques to present an ethnodrama in aiming to further engage readers in our findings. Overall, the findings presented herein illustrate the behavioral and cognitive decline of former athletes who have neurodegenerative disease, and further demonstrate the strain partners, siblings, and children of these former athletes feel during such times. In so doing, this research supports the work of Duff (2002), who reported a similar decline after interviewing a sample of family members of those experiencing a severe traumatic brain injury, as well as Faure and Casnova (2019), who sampled wives of former NFL players. Specifically, our ethnodrama highlights how a decline in memory caused the athlete to display erratic behavior, such as strange spending habits (that resulted in financial strain), not being able to carry out simple tasks or follow instructions, alongside increasingly aggressive behavior and, ultimately, a physical loss of functioning. The consequential strain of not knowing what was causing these behaviors impacted negatively on participants.

Furthermore, our findings support and extend the work of Duff (2002) and Faure and Casnova (2019) by illuminating the severe emotional consequences this decline had on family members, over different time points. Key emotional consequences included the confusion of not understanding what was happening, a sense of hopelessness and frustration of seeing such a decline in people they love, as well as not quite knowing what to do best to help and support their family member. Other emotional responses included embarrassment and shame (particularly when erratic behaviors were displayed publicly), fear for themselves and other family members when aggressive

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behavior was exhibited, as well as guilt due to feeling they failed in effectively helping and supporting their family member during their decline. Such findings should help practitioners, sporting governing bodies, and charities such as the CLF, understand more fully these negative emotional responses and, in turn, consider strategies that might be developed to support people in these situations.

The most prominent coping strategy we discovered participants engaged with came after the death of their loved one. We found that they used problem-focused coping strategies (Lazarus & Folkman, 1984) that involved striving to find answers concerning the illness of the athlete, with the understanding gleaned reducing confusion and bringing some relief. In some cases, such an understanding about the severity of the neurodegenerative disease brought comfort that this was not the caregiver's fault, but rather a product of living with neurodegenerative. Advocating for greater safety in contact sports was another strategy that participants used which made them feel like they could have a positive impact on others - who could learn from their experiences. Furthermore, attending 'The Huddle' appeared to be an effective coping strategy in itself; as conversations with others who had been through similar experiences, as well as the enhanced understanding they got from listening to research presentations about neurodegenerative disease, appeared to be very helpful.

On the other hand, limited coping strategies were employed by participants during the life of the athlete. Instead, most participants struggled to come to terms with the changes in their family member during this time. The most discussed coping strategy for these caregivers was that of intermittent escape, as a break from the strain of looking after their partner. Other participants also used avoidance strategies, for example, avoiding social situations due to their loved one's behavior. While our findings have illustrated a range of emotional responses during the life of the athlete, it appears coping strategies that family members might employ in this situation need further consideration.

The period of declining health of the former athlete might be the time that puts participants under the most strain, as well as being the period during which participants need the most support with regards to coping. Indeed, when participants reflected on this period, they outlined coping strategies that they might have used during these times. They highlighted that, with the knowledge they have now regarding neurodegenerative disease, they would care for the former athlete in a different way. In light of this understanding, they also suggested how they would reduce their expectations of the athlete's behavior, avoid setting boundaries on their behavior, and be more understanding and compassionate of the behavior they were exhibiting. Some participants also suggested how they were so busy looking after the athlete, that they didn't have time for themselves, and reflected on how looking after their own wellbeing might not only be good for themselves but, in turn, might enhance the care they offer to their family member.

This research leads us to suggest that there remains a need to learn more from the experiences of people who have been through this situation. This increased understanding might require qualitative approaches to specifically examine the experiences of people who have supported former athletes with neurodegenerative disease, and the advice and suggestions they have for others who might experience similar situations in the future. For example, future research might use other creative approaches, such as those employed by Szedlak et al. (2020), who used a reflective letter writing approach to encourage novice strength and conditioning coaches to learn from experienced coaches. In doing so, the partners and children currently living and caring for a former athlete with neurodegenerative disease can learn directly from those who have experienced this situation, allowing for their advice, support and reassurance to be shared.

Our sample consisted of partners, siblings and children of the deceased athlete, building directly on research concerning head injury in a sporting context (e.g., Faure & Casnova, 2019). The findings of the current study align with caregiving research in that partners effectively become the primary caregiver for the former athlete, due to their decline in health. For example, Whittaker

and Gallagher (2019) examined negative health impacts on caregivers, when the burden of caring is high, while Krutter et al. (2020) found a number of specific burdens placed on caregivers of dementia patients. Our work adds to this research by understanding some of the specific strains on those partners providing care for former athletes. However, all of the athletes in this study were male, often reported as having extrovert, positive personalities, making the behavior change as a result of the neurodegenerative disease feel more extreme. At the same time, the loss of sporting identity, with athletes no longer able to compete, might create challenging emotional responses from the former athlete (e.g., shame), potentially placing additional strain on their partner. Finally, many of the athletes were physically big and strong people. This creates practical challenges in terms of physically supporting the former athlete, as well as potential for physical danger to the caregiver if the former athlete were to become aggressive. As there are specific demands for those caring for former athletes with neurodegenerative disease, it is important that future research examines how such carers can be best supported, as well as considering interventions to help them, drawing on related literature (e.g., Carter et al., 2020).

A strength of the current study is the temporal nature of the analysis and the presentation of data. Similar to Haywood et al. (2016), who considered the stressors and coping strategies over a period of time amongst youth swimmers, as well as their parents and coaches, our temporal analysis allowed us to consider the stress-emotion-coping of participants at multiple time points. For example, we extend the work of Faure and Casnova (2019) by considering participant experiences, not only during the period of the former athlete's health decline, but also after their death. In addition, the innovative presentation of data as an ethnodrama, which builds on other creative approaches (e.g., Cavallerio et al., 2016; McMahon et al., 2017), means the results are accessible to a wider audience, increasing the likelihood of enhancing awareness and education around neurodegenerative disease. In presenting our data in a story format, as a play script, we hope multiple stakeholders will engage with our findings. For example, we hope that the evocative

dialogue will resonate with those who are going through similar experiences, while organizations supporting such people might disseminate these results. However, with our findings presented in a written format, further research might also want to consider other formats, such as audio and visual methods (Szedlak et al., 2019) of effective dissemination.

A limitation of our work was that while we considered the coping strategies used by participants, we did not directly consider coping effectiveness (e.g., Nicholls et al., 2006). Thus, future research might involve a more thorough examination of the effectiveness of coping strategies used by partners and children in this situation. Future research might also use intervention studies to consider the efficacy of the specific coping strategies highlighted in the current study. Finally, we acknowledge the retrospective nature of our study, and suggest that future researchers might want to consider designs that capture participant experiences of living with an athlete with neurodegenerative disease in situ.

In conclusion, we have advanced understanding of the strain faced by participants when a former athlete in their family declines in health due to neurodegenerative disease, as well as considering this over different time periods. We have also illustrated the (mostly negative) emotional impact this situation has on participants. This extends the work of Faure and Casnova (2019), as the findings demonstrate these impacts are much more widespread than just in professional sport, also occurring in families of non-professional players. Therefore, we have added to the growing body of work that highlights the considerable negative health impacts on those caring for individuals with deteriorating neurological health. Our findings illustrate how neurodegenerative disease has far reaching effects on sufferers and those around them, representing a growing public health concern and societal problem. As a result, greater recognition of the challenges faced by both those living with diseases of the brain, such as CTE, and their carers, is needed (Krutter et al., 2020). We also believe that the presentation of the data as an ethnodrama will engage a wide audience and encourage reflection on the strain faced, as well as the emotional

responses of people in this situation. In turn, we hope that this research may stimulate discussion and be disseminated to help support people who might be going through or go through similar experiences in the future, while at the same time considering how they might cope with the demands of such a situation.

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