

Negotiating Identity Conflict Through Football: Experiences of People Living with Type 1 Diabetes

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Negotiating Identity Conflict Through Football: Experiences of People Living with Type 1 Diabetes

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Abstract

Diabetes has become a condition which is acknowledged for its global impact on healthcare and society. However, much of sport research has followed a physiology focus that has increased awareness of the condition's effect on the body with a limited understanding around its socio-cultural consequences. This chapter fills this gap by exploring the identity conflict that footballers with Type 1 Diabetes (T1D) experience. Six male T1D football players were recruited and interviewed. Data were captured utilising a netnographic approach. The data were then put to a narrative thematic analysis. Participants demonstrated that athletic identity and elitism in sport adversely impact their identification with T1D. The data also revealed that the social-relational model of disability's connection with identity is the closest replication of identity negotiation between disability, T1D and participants. Stigma surrounding T1D was shown to have a significant impact on reducing identification with the condition, which was also linked to behaviour that negated medical advice and adherence to it. The Neo-Tribe concept offers an explanatory framework as to how identity conflict was negotiated through the temporary identification with T1D and the positive lever of football, driving an increased uptake in peer support and subsequent medical adherence.

Introduction

Diabetes mellitus is a medical condition that affects close to 4 million people in the UK alone, and the figure continues to rise (Diabetes UK, 2019). Despite the growing number of people affected by the condition and its social impact, research focus in sport has predominantly involved the management implications and physiological aspects of the condition (Jimenez et al., 2007). Although studies which investigate the social influence of diabetes within sport have recently emerged (Jaggers et al., 2016), research in this area is in its infancy. Given the scientific lacuna between diabetes and social sciences, there are multiple avenues to explore. Type 1 Diabetes (T1D) is classified as a hidden disability by UK law, but in relation to sport, the only participatory opportunity for people experiencing T1D comes in the form of mainstream sport (Equality Act, 2010). This contradiction is rare and further complicated by the distinction between Type 1 and Type 2 diabetes and that UK law designates very few cases of Type 2 Diabetes (T2D) as a disability (Diabetes UK, 2022).

Types 1 and 2 both fall under the umbrella term of diabetes, but there are key differences in the way they are managed and contracted (Diabetes UK, 2022). T1D is an autoimmune condition whereby the body attacks its own beta cells within the pancreas, which are responsible for producing insulin. Insulin is a vital hormone that moves glucose from the blood to cells to allow for the synthesis of glucose as a fuel when creating energy. There is no known cure for the condition or a clear understanding as to why it happens to certain people, but it leads to a life of exogenous insulin supplementation (Diabetes UK, 2022). T2D occurs when insulin is unable to work properly within the blood or not enough of it is produced to support the amount of glucose consumed or circulating. Often the treatment for the condition is improving diet and/or lifestyle as 50% of the cases relate to an unhealthy lifestyle or dietary choices (Diabetes UK, 2022). Therefore, the difference between Type 1 and Type 2 is that in some cases, Type 2 is avoidable

and reversible. Society has a tendency to attach stigma to diabetes because of the links between unhealthy lifestyle choices and some T2D cases. This social generalisation, however, has created a fissure between the types of diabetes relating to the identity of the community. Furthermore, given the dissonance between mainstream cultural narratives around diabetes and its sub-cultural perception, it is sensible to argue that identity formation associated with and within this community is a complex process which may influence the interaction of those living with diabetes with wider society (Cunnah, 2015; Carter, 2016).

The complexity of how the diabetes community's identity is constructed relates to broader issues around disability identity and classification for people with diabetes (Huang and Brittain, 2006; Fitzgerald, 2012). The medical model has been predominantly deployed to classify disabilities and designate the severity for conditions requiring the healthcare profession's support (Haegele and Hodge, 2016). This has given the medical profession the power to define what impairment and disability represent in society and sport, which has entrusted them with upholding legislative decisions that categorise health and illness (Howe, 2008; Kitchin and Howe, 2014). The health-illness binary narrative has created a unique scenario in relation to T1D and sport. To live with a disability that is not recognised in disability sport is an exceptional and, in many ways, challenging situation, for which the medical model's limitation is largely responsible. The narrow utility of the medical model regarding its practical and theoretical implications has been broadly recognised in academia, yet it remains the dominant paradigm in disability sports and adapted physical activity (Spencer & Molnár, 2022). The dominance of the medical model offers a possible explanation as to why there is still limited research around issues of disability identity for people with T1D and their complex identity formation in relation to football and sport more widely (Equality Act, 2010). Therefore, in this chapter, we explore how participants with T1D

and passion for football have managed and negotiated their identity within the context of an online peer support community through Maffesoli's (1996) Neo-Tribe theory.

Neo-Tribe is an established sociological concept introduced in the past 25 years to offer an explanation of the sub-cultures which exist within our communities (Maffesoli, 1996). The concept was formulated by Maffesoli (1996) to theorise coherent sub-cultures that present themselves in different groups of people. They are said to demonstrate gatherings without organisational rigidity, whose members share a similar state of mind, that can be expressed through lifestyles or ritualistic behaviour (Kriwoken and Hardy, 2018). Importantly, Neo-Tribes do not link to traditional, permanent or tangible entities through which pre-existing communities have been established. The concept recognises that society has moved away from traditional frameworks and structures to an existence that is more fluid in its approach to social positioning, networks and values (Best, 2013). With emerging trends around online communities emanating as a result of traditional networks failing to fully encompass a community's need, the principles behind a Neo-Tribe may provide an explanation for the continued growth of the number and range of online communities such as online health communities, an example of which is discussed in this chapter.

The Neo-Tribe is an emerging concept within the field of sport studies as communities continue to adopt differing formats, gradually moving away from traditional physical communities, with reliance on omnipresent online connectedness that helps to provide foundations for expansion, as well as a fluidity, that underpins the existence of neo-tribes. The study from Asan et al. (2021) is an exploration of the concept's existence within cycling. Their work studied the online interactions of two cycling communities to ascertain whether the common characteristics of a neo-tribe continued to exist within a sporting environment. They present a view that

demonstrates that the cycling communities continue to share values, concerns and a fluidity of identity that embody the main characteristics of a neo-tribe. This is congruent with Best's (2013) study; however, Asan et al. (2021) highlight the intensity of the 'feeling of us' which was a recurring reference to the togetherness seen within the community in their study. This feeling could be increased through exposure to sport, which encourages teamwork and can reinforce team culture and high levels of cohesion. Consequently, sport can heighten community cohesion striving towards those shared goals of sporting success and enjoyment. Given that shared concerns can enhance cohesion (Asan et al., 2021), it could be argued that the feeling of togetherness and the existence of neo-tribes in sport may be amplified when influenced by a medical condition such as diabetes. However, Asan et al.'s (2021) study has focused on cycling, an individualistic sport, which may have an impact on participants' desire to engage, as they are often less reliant on team connections. This does not appear to be the case in football that is a team sport, but the existence of neo-tribe-type cultures within and in relation to it is still under explored. Nevertheless, Asan et al.'s (2021) study is pertinent to this chapter as they suggested that a chronic illness would strengthen a Neo-Tribe's cohesion and increase interaction, which, in turn, may help contribute to the explanation for TDFC's (The Diabetes Football Community) success as an online sport and health community.

Yet, it is the choice between identification and non-identification with diabetes that seems to offer a stronger potential foundation for Neo-Tribe formation within the work of TDFC. The principles behind the Neo-Tribe concept may present an explanation for the creation of values that underpin TDFC (2022). Shared values and experiences, the fluidity of identity and the absence of a pre-existing community to identify with jointly replicate some of the key characteristics that a Neo-Tribe demonstrates (Best, 2013). When considering that TDFC (2022)

presents a new formation of a community, created online, with members all living with the same chronic health condition, the potential for association with the Neo-Tribe concept becomes evident. Adding to the above list the temporary identification that online communities can offer, which may involve an infrequent post or a one-off engagement in a physical or online discussion, further connections can be detected (Hardy et al., 2012).

The ease of access to and flexibility of identification with the group's purpose may enable a transition to associate with T1D, a condition adversely framed by the medical model of disability (Haegele and Hodge, 2016). Consequently, pertinent questions to consider are whether TDFC (2022) is a Neo-Tribe? Does the potentially fluid identification with the community and stigma surrounding T1D make interaction in this instance easier than a traditional community? As members of the community can create distance between their condition and community engagement as a result of the intermittent nature of interaction in community activities, as well as an irregular identification with the values and purpose of TDFC (2022), the Neo-Tribe concept may help with our understanding as to why this online sport and health community has been successfully established. Therefore, it is possible to postulate that the concept of the Neo-Tribe in the TDFC context has utility in understanding the negotiation of identity in relation to diabetes, which has social stigma, through temporary, infrequent and self-determined interactions such as social media posts, reading blogs and engaging in online forum chats provided by TDFC. Furthermore, the Neo-Tribe concept may deepen our understanding of identity formation in this group concerning the interplay between their condition and community, which, in turn, may help ascertain future treatment pathways, thereby moving towards greater engagement with medical advice, such as the use of peer support communities.

Methods

To explore the experiences of the participants involved in TDFC and understand their motives and feelings, a qualitative approach was utilised (Huang and Brittain, 2006; Perrier et al., 2014). The study followed a multi-method approach involving a case-study design, which explored the community's interactions through semi-structured interviews and netnography (Cunnah, 2015). To recruit participants, the process was similar to that of the work of Smith et al. (2016), whereby social media was utilised to communicate the research and need for participants who fit a number of inclusion criteria (Sparkes and Smith, 2014). Six male T1D football players were recruited for this study. Utilising an interview schedule devised to guide the process, each participant was interviewed once examining concepts including disability identity, community formation and peer support. To build upon the semi-structured interviews, a netnographic approach allowed for data collection from TDFC (2022) website, Facebook and Twitter pages, from which the project originates, to understand its establishment and continued development. The posts captured include the top five performing blog posts, top five Facebook page posts and top five tweets based upon views and likes, respectively (Zhang, 2016). Online content and interview transcripts were put through thematic analysis (Wang, 2019). To do this, the raw themes were identified from the interviews and participants' posts expressed on TDFC media channels. Participants are represented by pseudonyms in the sections below.

Stigma – A Cause for Identity Conflict?

Goffman (1963) argued that deviating from dominant characteristics and qualities held throughout society creates a spoiled, undesirable identity. This leads to the ostracisation of non-conforming members and low perceived value of them within social hierarchies. Through the widespread adoption of social labelling, which reinforces cultural meanings associated with a

term, self-identity can be impacted. This effect is particularly potent when a term acquires a negative connotation (Li and Moore, 2001). As T1D is classified as a hidden disability (Equality Act, 2010), the word disability suggests that the beholder has a lack of aptitude or skill which drives a negative perception of those associated with the condition (Zhuang et al., 2017). Consequently, it may be argued that disability is associated with low expectations and a perception of weakness around those who experience such conditions which can be seen by the accounts of participants (Zhuang et al., 2017). When asked about T1D-related negative social perceptions, many participants recalled instances and their feelings around stigma. David explained that

I know society's perception of, not the condition diabetes, but the word diabetes, and what people relate it to. Then I just thought if someone looks upon me as a person, as a whole, as it was if I'd been for a job interview they could, possibly, see it as something that's a negative to me as a person.

Participants demonstrated their view of society's perception of T1D contributing to a feeling of shame derived from living with the condition. Society's interpretation of the word diabetes and its meaning is a real-life experience of stigma, a perception that the condition was self-inflicted and avoidable as well as highlighting the negative attitudes towards disability (Green, 2003). That is, even though this condition was not self-inflicted, participants have been labelled with an unfavourable association. Stigma impacting people with a health condition has been expressed in other works focusing on HIV/AIDS, mental health and T2D (Browne et al., 2017). In fact, one of the issues for participants was around the lack of understanding of diabetes and confusing T1D and T2D. Jordan explained:

They [T1D and T2D] get grouped together by using the same word, and then just changing a number on the end. Yeah, I guess people have got their feelings on Type 2 that it's due to your unhealthy lifestyle and poor diet, because that's what society leads them to believe and that's the reason why someone would have Type 2... I think they're both conditions that you need help with, obviously, but it would make it much simpler if they were called different things.

As T2D equates to 90% of diabetes cases, most of society's understanding relates to this version, despite a significant number experiencing T1D (circa 400,000 people in the UK). T2D has been attributed a social stigma which is recognised by Browne et al. (2013). However, society's confusion around diabetes has seemingly led to a divide in the diabetes community within which people with T1D have grown frustrated as they are too associated with negative connotations that do not reflect their condition. The division has been reported by Browne et al. (2014) but has not been recognised in a sporting setting, where weaknesses are frequently shunned as those may accentuate the potential for disassociation with and acceptance in sport (Brittain, 2004). Consequently, understanding how the conflation of T1D and T2D impacts on condition management, health and identity is vital in informing future treatment pathways. Nevertheless, participants noted that they had adopted their own coping mechanism to manage social stigma associated with the conflation of T1D and T2D. David explains:

I've hidden it for a good 20 odd years, as a feeling of being different to other people... Before I had the confidence to treat my diabetes in public, I'd go out for a meal where I should be injecting before, I'd leave right up until I got home to inject, which would then [make] my blood [sugar] go high and I'd have all the problems of that. So, it affected my own care for myself.

Highlighted is the impact that stigma has had on the decisions participants made about treating their diabetes to feel accepted in society, which meant hiding their identification with diabetes. Society continues to uphold stigma for disabilities which continue to demonstrate a difference to the majority (Goffman, 1963). Cunningham and Pickett (2018) showcased this through the stigma connected to bodyweight which is easily exercised via visible corporeal deviation from societal norms. However, T1D compares closely with mental health stigma through the invisibility of the conditions. Smith and Applegate (2018) showcase the enduring widespread stigma linked to mental health, which continues to impact on accessing help that furthers the likelihood of adopting secrecy to cope with the conditions. This is congruent with the work of Buttgieg et al. (2017), who suggested that the social stigma surrounding diabetes disrupted self-management whilst highlighting secrecy as a coping mechanism (see also Gredig and Bartelsen-Raemy, 2017). Rather than making choices that would mean better results and control for their T1D, participants expressed that they would rather behave in a way that conforms to society's expectations, despite the need to effectively manage their condition.

Identity – Disability – Diabetes

Interestingly, there is little literature referring to sports-specific T1D communities, the effect of elitism and its impact upon hiding perceived weakness by those living with a chronic illness (Trejo et al., 2017). There is also a low level of open diabetes identification amongst those living with T1D involved in elite football (Commissariat et al., 2016; Cunningham and Pickett, 2018). People with an athletic identity and T1D fear that by showing weakness they are assigned a stigma, which, in turn, could impact their athletic career and lead to limited self-management (Cosh et al., 2013; Commissariat et al., 2016). Coupled with the social expectation that athletes

are supposed to embody health and peak performance, the fact that athletes experiencing T1D require exogenous insulin to survive yet compete within mainstream sport also troubles that image. To preserve the idea of corporeal health and peak performance, athletes may resort to hiding the condition (Fitzgerald, 2012). Liam explains:

That stigma about male sport is a case of, it's alpha male. You have to be seen as untouchable and it's for your own self-worth and you know as well as I do, you walk out on that pitch and if you don't feel like you're untouchable and you're the best on that pitch then you're giving away an advantage. And if you think you'll be seen as that [having T1D] and that's given them an advantage then you do yourself... a disservice.

The need to show no weakness and appear 'untouchable' is unsurprising given that elitism is promoted within sport (Bailey et al., 2016; Buttgieg et al., 2017). However, it is evident from the narratives that having a hidden disability is emotive, personal and debated in the T1D community. As T1D is classified as a hidden disability under the Equality Act (2010), the medical model seems to be dominant as to how those living with the condition are perceived and treated (Fitzgerald, 2012). However, the perception of people living with T1D and their interpretations as to whether it is a disability differs from the identity prescribed by the medical model.

Members of the community demonstrate a divided view around T1D as a disability. Mark showcases these perceptions:

I've had this question on questionnaires a few times. I would also tick no because I like to think that I can live without needing any particular, special support. Although, I do feel it would be good as a diabetic to know that you would have that support if you need it. There

are times in case of an emergency where I think it definitely comes under the disability category.

This dualistic perception of T1D in relation to it being or not being a disability indicates a clash between the medical and social models of disability (Huang and Brittain, 2006; Cunnah, 2015). Both models suggest that the power to bestow disability identity upon someone is outside of the individual's control and is performed by either the medical profession or society. However, interviewees revealed that their own experiences of disability are complex and shifting, which demonstrates a closer link to the social-relational model. Importantly, as T1D is invisible, besides blood glucose monitoring and administering insulin, the hidden element allows the adoption of secrecy as a coping mechanism which provides greater autonomy around disability identification for this group. It is also seen through the participants' use of 'I think' and 'I perceive', which suggests that they hold some power in the way they view themselves in relation to disability, to which people experiencing other types of disability may not be able to relate. Therefore, the social-relational model and its focus on connecting lived experience with the impact of society and medical professionals are a closer representation of the disability identification process of those living with T1D and may also help underpin engagement levels with their condition and projects like TDFC (Campbell, 2018).

Neo-Tribe and the Football Community

Participants' views reveal that after becoming part of TDFC, they experienced a shift towards pride for living with T1D, an acknowledgement of support and shared experience as well as an ability to communicate and share through social media. By utilising social media, participants could remove geographic barriers, create aliases, participate when and however they preferred or

even just ‘lurk’ (see Thomas et al., 2016). By having the opportunity to participate in TDFC (2022) and identify with it through the use of social media, the concept of the project portrays key characteristics of a Neo-Tribe (Kriwoken and Hardy, 2018). Jordan showcases those values in this account:

I see on social media all the time people sharing positive stories of people with Type 1 diabetics, whether it's children, player of the match, or scored a goal, or people just having little wins. I just think it's so proud to be part of that community.

A Neo-Tribe is a type of sub-culture, where an organisational impact has not yet been felt and members share a similar state of mind which is also expressed through their behaviour (Best, 2013). The concept suggests that the dissolving of unity within existing societal structures has paved the way for more fluid movements of people, in which those associated will not label themselves with one particular identity but instead move between numerous groups (Dedman, 2011; O'Reilly, 2012). Its premise aligns closely with the foundations of TDFC (2022), and participants' accounts demonstrate a clear connection to its values and purpose. As society has moved away from traditional frameworks to social positioning, values and networks in favour of a more fluid approach, there has been a space afforded to online communities which, in this case, may present through the concept of Neo-Tribe (Best, 2013). As TDFC (2022) is connected to social media as a movement that embodies shared values, a new form of networking and a new approach to anything society had provided before for this population, it again stands to reason that a Neo-Tribe may provide the closest representation as to how this emerging community has come to exist. Hardy et al. (2012) explored a population within a sub-culture which experienced a fluid identity that shifted through their temporary experiences together and the multiple facets of the group's identity. As participants had been grappling with an identity linked to T1D which

is stigmatised, the opportunity to temporarily access that identity to seek out positive experiences through TDFC seems conceivable. This helped participants gain T1D-related information, peer support and an acceptance of their condition, whilst utilising football, which embodies desirable social attributes, to support with their T1D whilst potentially avoiding some of the stigma attached to the condition (Snelgrove, 2015). By participating in TDFC in a temporary way, stigma could be avoided, identity towards their condition may be enhanced and, as Browne et al. (2013) suggest, this may also have a positive impact on their long-term self-management of T1D through greater levels of acceptance and adherence. Therefore, in establishing a movement through social media, TDFC has embodied the characteristics of a Neo-Tribe, which may have also aided with navigating a stigmatised identity for those with T1D through the use of an online peer support community (Hardy et al., 2013; Browne et al., 2014).

Conclusion

The form that TDFC has taken on is an emerging topic for academia to contemplate when addressing a stigmatised group of people living with a chronic illness. When considering the frustration at the social stigma that this T1D population feel, and subsequent reluctance to associate with the condition through fear of non-acceptance in an elitist masculine football culture, it would seem that the cohort would be destined, as referenced by the literature, to a lack of identification with their condition which leads to poorer self-management outcomes (Gredig and Bartelsen-Raemy, 2017). However, TDFC (2022) has brought about change for this population in how they view and interact with the condition, which demonstrates close links to the sociological concept of Neo-Tribe (Hardy et al., 2012). The temporary acknowledgement and identification with the condition allow the participants to engage with T1D on their own terms,

without the pressure of traditional communities (Zhao et al., 2015). Nevertheless, the main reason for engagement with their condition in this population is because the community is built upon their interest first. Football as a sport with a widespread appeal is positively viewed across the world, and in this population, in particular, it is a large part of with what they self-identify. Football may have presented a problem for this community previously with its cultural perception of illness that those living with the condition found difficult to overcome. However, the sport through this project now links participants to their condition positively, which has aided identification with T1D that may never have occurred otherwise (Browne et al., 2014). Instead, through the adoption of a positively viewed sport, combined with the opportunity to temporarily identify with T1D through the use of social media, a group of people have found a way to meaningfully connect with their chronic condition. In providing a platform that has connected a population to their condition, potentially for the first time, greater health outcomes may be achieved (Browne et al., 2014). This embodiment of a Neo-Tribe, utilising football, to positively link participants to their condition is one which future research and healthcare professionals should consider when enhancing future treatment pathways for those living with chronic illness.

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