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The psychosocial impact of losing an eye through traumatic injury and living with prosthetic restoration: A thematic analysis☆

Joni Keysa, Martin Dempstera,b, Jonathan Jacksonc, Michael Williamsb, Sinead Coylec

a School of Psychology, Queen’s University Belfast, University Road, Belfast BT7 1NN, UK
b School of Medicine, Dentistry and Biomedical Sciences, Queen’s University Belfast, University Road, Belfast BT7 1NN, UK
c Artificial Eye Service, Belfast Health & Social Care Trust, Shankill Wellbeing and Treatment Centre, 83 Shankill Road, Belfast BT13 1FP, UK

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ABSTRACT

This study aims to explore the psychosocial factors and challenges affecting the lives of those who wear an ocular prosthesis following a traumatic eye injury. Thematic analysis of semi-structured interviews with eight individuals resulted in five themes: emotional devastation in the aftermath; moving forward; fear of negative social isolation and suicide; (Thompson & Kent, 2001; Rumsey et al., 2004). Visible differences to the face may impose particularly complex psychosocial challenges (De Sousa, 2010; Rumsey & Harcourt, 2004) and disfiguration to key areas such as the eyes, nose and mouth may increase susceptibility to distress (Bradbury, 2012; De Sousa, 2010). Furthermore, subjective satisfaction significantly influences psychosocial outcomes (Mox, 2005; Thompson & Kent, 2001).

Whilst recent years have seen a sizeable growth in research focused on the psychosocial aspects of ‘visible difference’, there is a paucity of research exploring psychosocial adjustment in those living with the prosthetic restoration of an absent part of their face (Yaron et al., 2017; Yaron et al., 2018). The absence of literature exploring the nature of psychosocial difficulties experienced from patients, who are best placed to understand the impact of disease, limits evaluations of current programmes of care (Dean et al., 2017). Furthermore, there are scant data exploring psychosocial issues that may be present in those who have lost an eye due to trauma, for example following an accident or assault. Such an event is obviously sudden and unexpected, and surgery to remove the eyeball in these circumstances is usually needed within days of the injury. This is in contrast to having an eye removed as it has become both blind and intractably painful, when the patient may have thought about and discussed removal of the eye for months, and may be glad to become pain free.

1. Introduction

A visible difference has been defined as a “difference from a culturally defined norm which is visible to others” (Rumsey & Harcourt, 2005, p. 88). Research suggests those living with appearance altering conditions are at risk of anxiety, depression, stigma, discrimination, social isolation and suicide (Thompson & Kent, 2001; Rumsey et al., 2004). Visible differences to the face may impose particularly complex psychosocial challenges (De Sousa, 2010; Rumsey & Harcourt, 2004) and disfiguration to key areas such as the eyes, nose and mouth may increase susceptibility to distress (Bradbury, 2012; De Sousa, 2010). Furthermore, subjective satisfaction significantly influences psychosocial outcomes (Mox, 2005; Thompson & Kent, 2001).

To allow for better understanding of the experiences of this patient group, and the subsequent development of rehabilitation programmes responsive to patient need, richer conceptualisations of the specific nature of their psychosocial difficulties is needed. Previous research has considered heterogeneous samples with different types of prostheses (Yaron et al., 2017; Yaron et al., 2018). The absence of literature exploring the nature of psychosocial difficulties experienced from patients, who are best placed to understand the impact of disease, limits evaluations of current programmes of care (Dean et al., 2017). Furthermore, there are scant data exploring psychosocial issues that may be present in those who have lost an eye due to trauma, for example following an accident or assault. Such an event is obviously sudden and unexpected, and surgery to remove the eyeball in these circumstances is usually needed within days of the injury. This is in contrast to having an eye removed as it has become both blind and intractably painful, when the patient may have thought about and discussed removal of the eye for months, and may be glad to become pain free.

1.1. Research aim

The current study aimed to explore the nature of psychosocial challenges encountered by individuals living with an ocular prosthesis following trauma. Previous literature suggests individuals who experience appearance alterations as a consequence of traumatic injury to the face may be at an increased risk of negative psychosocial sequelae compared to those who have acquired visible difference through disease (Newell, 2000).

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* Corresponding author.
E-mail address: m.dempster@qub.ac.uk (M. Dempster).

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2. Methods

Individuals who wore an ocular prosthesis as a result of a traumatic injury to their eye were recruited from a regional artificial eye service. To minimise the impact of post-surgery adjustment, participants were at least two years into rehabilitation. Participants were aged 18 years or over, had normal functional vision in the remaining eye, had capacity to provide informed consent, could converse coherently in English and were not going through any legal processes related to the original trauma.

Ethical Committee approval was granted by a NHS Research Ethics Committee (16/NI/0255). A case review identifying all patients meeting inclusion criteria was completed by the prosthetist in the service and invitation packs were posted to the first ten potential participants. Further packs were then sent out in response to study uptake and ended at saturation, i.e. when no ‘new’ codes could be identified within the data item (Saunders et al., 2018). For those participants who provided written informed consent to take part in the study, the interviewer made contact (JK, a female trainee clinical psychologist previously unknown to participants). The consolidated criteria for reporting qualitative research (COREQ) was used to report key aspects of the research team, method, context, findings, analysis and interpretation (Tong et al., 2007).

Data were collected through one-to-one interviews using a semi-structured interview schedule. All interviews took place in private at neutral venues, lasted between 50 and 100 min and were audio recorded. Interview questions were open ended and aimed to gather respondents’ perceptions of the psychosocial impact of eye loss and prosthetic restoration across different aspects of life.

Interviews were transcribed verbatim immediately after each interview. The first transcript was reviewed by the second author to ensure questions suitably tapped into relevant information.

Thematic analysis (Braun & Clarke, 2006) was used to analyse the data. Guidelines from Braun et al. (2019) were followed, along with Nowell et al.’s (2017) guidance on meeting trustworthiness criteria in thematic analysis. With focus on experiences and meaning, the study is phenomenological in nature, however with the incorporation of the ways in which wider society influenced experience and meanings, it retains a contextualist position. Considering lack of prior research in the area, and the exploratory nature of the research question, an inductive thematic analysis was used, where coding and theme development were directed by the content of the data.

Phase one of data analysis involved ‘immersion’ by reading the entire data set initially, then re-reading each transcript. Phase two focused on ‘generating initial codes’ by systematically engaging in complete coding for each data item, recording as many data driven and researcher-driven codes relevant to the research question as possible. Analytic focus was then shifted to reviewing and refining initial codes, ensuring relevance to research question, reducing overlap and ensuring differentiation between concepts and ideas. Phase three focused on the search for and development of themes which captured the most salient and meaningful aspects of the data in relation to the research question. The construction of themes was aided by the ‘cutting and sorting approach’ as described by Ryan and Bernard (2000) and visual diagramming using picture boards. At this stage, data was reduced into a more manageable set of significant themes, that was felt to summarize the text (Attride-Stirling, 2001). During phase four, themes were reviewed to ensure data that is thematically similarly had been grouped together meaningfully, with clear distinctions. The credibility of themes was assessed by returning to the raw data to ensure themes were firmly grounded in the data (Tobin & Begley, 2004). Discussions with the second author took place at this stage to review the validity and coherence of themes. Phase five concentrated on defining and naming the themes. During phase six, overarching themes were presented to wider members of the research team with justification of the development of these themes and demonstration of how they are related to the transcripts.

3. Results

Sixteen invitation packs were sent to potential participants; eight were recruited. There were 6 males and 2 females, age 22 to 55 years, who were 3-12 years post injury. There were 5 enucleations and 3 evicerations.

The analysis resulted in five candidate themes: emotional devastation in the aftermath, moving forward; fear of negative social evaluation; keeping it normal - protecting self and close others; and threat of injury & blindness.

3.1. Theme 1: emotional devastation in the aftermath

Diversity arose in the aspects of the injury respondents experienced as most distressing in the immediate aftermath. For some, the pain associated with the initial trauma and subsequent enucleation or eviceration and the ongoing healing was a major issue. For others, adjusting to monocularity, was most distressing. Respondents often found themselves frozen in a state of shock and despair and reliant on loved ones to provide basic needs for many months post injury:

“it was a traumatic eye injury so it took me a long long time…my husband had to bath me. I was lying in bed out of it for like say about 9 months…I thought ‘when am I ever going to get my life back?’”

(P2)

For some respondents, facial disfigurement was the most harrowing consequence of injury and enucleation or eviceration, grieving for their former appearance and facing the challenge of accommodating an unwanted altered appearance into a new self-identity, whilst experiencing shaming, stigmatizing stares and comments from everyday strangers. Isolated in their experience of post enucleation or eviceration disfigurement, respondents described feeling disconnected from themselves, and close friends and family. For some, the experience of disconnection from close interpersonal relationships was exacerbated by the sick and disabled role imposed on them by loved ones after their injury:

“the way people were treating you… treating you like as if …like …you were dying or something like that or god forbid you had cancer or something like that or there or you were handicapped or something you know …know what I mean but that was all eating me with people you know you know what I mean.”

(P7)

The practical and emotional implications of visual impairment and monocularity on employment were the most challenging consequences for other respondents, with the loss of an eye meaning they could not return to their pre-injury careers, careers which, had brought self-esteem.

“not being able to provide for your family like and then not being able to work or, like, where do I go from here, or, like I didn’t know what I was going do and, think that was maybe more of a problem like, more than anything else.”

(P8)

Whilst diversity arose in which aspects of their injury respondents found most distressing, there were significant commonalities in the descriptions of emotional devastation post injury. Overwhelmed by the disruptions the injury inflicted on their internal sense of self and safety, respondents described their experience of feelings of hopelessness, depression, grief and isolation. These emotional experiences were complicated for some by scrutiny of whether their own actions had led to their injury, engendering a sense of self-blame. Some respondents endeavoured to hide their distress, putting on a front to the outside world that everything was ok, using excessive amounts of alcohol to

(P2)
3.2. Theme 2: moving forward

Theme 2 encapsulates respondents’ reports of a conscious realisation that to move on from the emotional devastation they experienced in the aftermath of their injury, they needed to accept that injury had happened and start the process of reclaiming life:

“I mean you could stay static in one place and you know, feel this, and it was an awful thing to happen and it was really difficult at times but if I had stayed in that place emotionally and psychologically you know there’s the chance that’s where you stay.”

(P3)

All respondents cited family support as a resource instrumental in their move forward after injury: “if I hadn’t had my family and friends I be a beaten docket”, (P7). Respondents described capitalising on strengths within their family to build resilience. For some respondents having a strong family narrative that ‘challenge demands confrontation’ helped to inhibit the development of avoidant coping mechanisms. For others, it was the adaptability of family members to assume new roles within the family, that facilitated recovery and their move forward. Respondents described using the safety and security of the family unit to develop confidence in talking about their injury, its impact and learning to use humour to normalise the everyday challenges and limitations of monocularity. Respondents described learning to talk openly about their injury, and relating to the injury in a more humourous manner, as forerunners to communicating with others about injury outside of the home:

“If we didn’t start making a joke about it or didn’t start talking openly within the family then that would nearly have made it worse and probably made it harder for me to deal with it.”

(P3)

Respondents also reported drawing on internal psychological resources to enhance resilience. For some, the capacity to reflect on past adversities instilled a sense of hope that life could, and would, continue after adversity. To lessen feelings of victimization and isolation, respondents also widened their initial perceptions and evaluations of the impact of their injury as life limiting, by comparing the severity of their injuries with the experiences of less fortunate others:

“I just looked upon it that you know, yes I’ve lost my eyesight, wouldn’t it have been worse if I had been in a wheelchair, you know even worse for my family, if I had died you know.”

(P2)

In the same vein, with time, respondents’ awareness of the transient nature of emotions grew and they were able to draw on this learning to help live alongside difficult emotions instead of struggling with them, demonstrating an increase in psychological flexibility (Hayes et al., 2006).

“I would be very emotionally aware so I know if I’m feeling a bit down and I know if I’m feeling a bit crabby (short tempered), I know what I need to do... I’m very aware that how I feel is different from day to day.”

(P3)

Furthermore, respondents skillfully honed internal psychological resources such as self-determination and mastery, to once again become proficient in many aspects of life which had been significantly impacted by monocularity, activities including self-care, driving and hobbies, and confidence grew as small goals were accomplished, giving further motivation to overcome other limitations:

“You feel the confidence know what I mean, ‘I can do that again now’, you know what I mean so that’s what I started working on (.) and now it’s got to the stage now I love a challenge.”

(P7)

3.3. Theme 3: fear of negative social evaluation

Step by step, year by year, respondents managed to renegotiate a way forward in life, using inner strengths and resilience to re-cultivate a sense of value, pride or direction which included for many, a rethinking of work and career. However, the usual appearance of their artificial eye continued to attract unwanted stares and glances when in public spaces or in close encounters with others unknowing of their injury. Within this context, when sharing public or social spaces, respondents continued, often many years post injury, to experience intrusive thoughts; “they think I’m some sort of cross-eyed boyo” (P5) and images “weirdo” (P5); “crazy” (P3); and “robot”, (P4) of how everyday strangers might perceive them. Along with the embodied sensory experience of their artificial eye as ‘different’ from their natural eye and the potential for their prosthesis to fall out, these experiences perpetuated ongoing fears of negative social evaluation: ‘I think maybe they are judging me or looking at me”, (P1) and evoked feelings of alienation and abnormality:

“To live a normal life is all I really want you know, I just want to blend in, be normal, a normal citizen really without all the looking and you know all the other problems of meeting people.”

(P4)

To manage appearance related anxiety and fears of negative social evaluation, respondents engaged in various strategies evolved to minimise the visibility of their eyes. These included wearing their hair in particular styles and applying make-up, avoidance of eye contact or the propensity to turn their head frequently when addressing people so to minimise noticeability of the lack of motility of their artificial eye. Respondents noted that these strategies were in contrast to commonly accepted social skills “I would never really look at a person as much as I probably should do” (P1). For some, to avoid the uncomfortable physiological experiences accompanied by social anxiety, they chose to stay at home during the day, going out at night where possible: “I’m much more about a night time kind of a guy now” (P4). Whilst fear of negative social
evaluation arose predominantly in relation the appearance of their artificial eye, respondents also continued to experience negative stigmatising reactions from unknowing others, as a result of visuospatial deficits, experiences which also continued to perpetuate distress.

“You say to people if you bang into them ‘sorry I didn’t see you’ and they tut and there’s times you just want to grab them and say look ‘I am blind to that side, I genuinely didn’t see you, I’m very sorry’, it’s horrendous.” (P2)

Many respondents expressed a belief, that if people knew of their experience of injury, this would reduce their worry of negative social evaluation and feelings of shame and stigmatization, as strangers or unknowing others would attribute appearance alterations or visual impairments to the impact of injury, and not as a result of inherent personal flaws: “Maybe it could be a better relationship if they maybe knew about it I think… it would make me feel more comfortable in talking to them” (P1). In this context, respondents described finding ways of communicating openly, where appropriate, that they wore an ocular prosthesis and this helped to manage their worries and gain a sense of control. For some, this meant looking for the right opportunity to talk openly about their “dodgy eye” (P3) or their “accident” (P5) or for one respondent tapping her prosthesis with their finger to highlight the falseness of their eye: “I’m always sticking my finger in it, just to make sure that people know” (P2). In the absence of opportunities to communicate openly and directly, respondents found alternative ways to communicate the invisibility of their injury and impairment such as using a “white stick” (P2) or the adorning of an eye patch:

“I ended up wearing like a black patch, literally just like a pirate but it’s I don’t know I suppose I really hated how I looked. I could cope with people’s comments about the patch much easier than I could cope with the comments about or if people were looking at me for my eye because I think at least then with the patch you know in general people would have known that there was something wrong.” (P3)

3.4. Theme 4: keeping it normal - self-protection in close relationships

Whilst for most, stigma, shame and fear of negative evaluation arose when outside of the home, in the company of everyday strangers or unknowing others, for some, a sense of shame connected with their appearance, continued to subtly infiltrate more intimate or personal spaces with partners or friends: “You’d be conscious of it and even with me wife like, it’s an awful, I suppose, an awful thing for her too like” (P8). For some respondents, to protect against feelings of shame that accompanied exposure of their true appearance and eye socket, they sought to prevent their loved ones from seeing them without their prosthesis: “I’d never ever let him see me without it” (P3). For others, feelings of distress at the unveiling of their uncovered eye socket were bi-directional and their partners adopted a preference not to see them without their prosthesis:

“My husband would never want to see my eye out you know but I do that take it out and clean it myself you know, I just keep my sunglasses on then if I have the eye out. I do have a wee patch that you could put on but then you feel like a pirate you know but, you know, you try to make it as…as normal as possible for yourself.” (P2)

To promote a sense of normality within the relationships, and avoid shameful feelings connected with their artificial eye, respondents implemented a deliberate avoidance of talking about the artificial eye, perhaps, paradoxically, preventing the assimilation of ‘different eye’ as normal in the longer term:

“I was saying to her like ‘I’m going to get a new eye tomorrow and all’ and she was like ‘why don’t you tell me all this stuff?’, and I was like ‘cause I just want to get on with it if you know what I mean’, just wanna get the new eye in and then just go on about my daily business.” (P1)

Despite wearing their prosthesis some respondents felt vulnerable within their peer group, finding themselves the butt of jokes, through their comparison with infamous characters from movies. Whilst this experience of stigma increased feelings of anger and social disconnection, it also induced feelings of powerlessness, as it needed to be endured and internalised as a normal social group process should they wish to retain some grasp of a viable social standing or else be cast further into the role of a person to be pitied:

“I go into the bar and well ‘one eyed willy’ you know and I don’t mind that now right it’s a bit of craic (fun)... if I start taking things thick or anything like that it does get at you.” (P7)

3.5. Theme 5: threat of injury and blindness

Whilst stigma associated with appearance and visual impairment continued to impact respondents lives, many also reported an ongoing preoccupation with physical safety arising from their reduced field of vision and deficits in depth perception: “depth perception seems to be a problem and it’s not something that I’ve really come round on like” (P8). Preoccupations with physical injury were perpetuated by respondents’ experiential learning that ‘bad things do happen’ and by the looming threat of blindness should anything happen to their remaining good eye. Respondents reported that living with a heightened sense of danger and need to ensure their physical integrity, meant they lived each day with a heavy sense of caution and consideration: “I have to be very very wary about my good eye because I don’t want to be on a white stick right, it’s just, it could just happen so easy you know so I have to be very careful” (P7), not only in respect of their own safety, but the safety of others who may come to harm as a result of their visual impairment. Preoccupations with harm, injury and blindness served to threaten respondents’ sense of autonomy as they found themselves reliant on others to ensure safety in certain situations, which before their injury, they would have faced with confidence. Furthermore, an increased perception of the risk, danger and the vigilance required to protect against this felt so overwhelming for some respondents, they disengaged from social activities that had been part of life pre-injury, inadvertently, perpetuating their risk of social disconnection and isolation.

“You stand back a lot you know. I have to sort of take everything from…. it’s everything in life really from a back perception.” (P2)

Reflecting on the ongoing nature of their psychosocial challenges, respondents reported, that whilst they had arrived at a place where they felt they had a good life and had grown as people as a result of their experiences, with an increased ability to relate empathically to others, they continued to encounter very difficult days emotionally, even many years post injury. Recognizing that the psychosocial challenges they faced as a result of their experience would change as the contextual factors of their life evolved, respondents reported that living with a prosthetic eye was not something they envisaged they would ever ‘be over’ or something that would ever become their new normal.
4. Discussion

Consistent with previous research into the psychological impact of facial trauma (Choudhury-Peters & Dain, 2016; Wilson et al., 2018), respondents experienced significant emotional distress post injury, reflected in the content of theme 1. Distress stemmed from a myriad of complex issues including disfiguration, monocularity, functional limitation, unemployment and pain.

Emotional devastation and functional impairment attenuated in time for this population of participants, a finding supported by previous research (Korani et al., 2021; Pine et al., 2017b). However, despite the acquisition of coping skills (theme 2), respondents continued to experience stigmatization and fear of negative social evaluation, reflected in themes 3 and 4, and preoccupation with ongoing fear of injury and loss of sight in the healthy eye (theme 5), many years after their injury.

Health of the remaining eye has been identified as the most common concern for people who have been wearing a prosthetic eye for at least 2 years (Rokohl et al., 2018).

Respondents experienced an element of psychological growth associated with their experience of traumatic eye loss, demonstrated in an increased capacity to relate empathically. However, the enduring nature of the challenges respondents faced continued to threaten feelings of competency, confidence and autonomy, increased risk of social isolation and inaugurated feelings of interpersonal disconnectedness and low mood. This meant that living with an artificial eye following a traumatic injury was not something to get adjusted to, but lived and coped with, on an ongoing basis. Previous research suggests that this adjustment is a process successfully negotiated by most but a minority continue to experience significant emotional difficulties, with younger people who are socially isolated most at risk (Pine & Pine, 2020). Indeed, the levels of anxiety and depression among people wearing prosthetic eyes might be underdiagnosed in practice (Heindl et al., 2021).

By highlighting the psychosocial challenges represented by traumatic eye loss and monocularity, in addition to appearance related distress, the present findings go beyond current understanding of distress for this population, offering a more holistic understanding of the psychosocial challenges faced.

These findings are consistent with previous research identifying fear of negative evaluation, social anxiety and social stigmatization, as frequent difficulties in those living with appearance altering conditions that can lead to social withdrawal (Clarke et al., 2013; Pine et al., 2017a; Rumsey et al., 2004; Rumsey & Harcourt, 2004).

The current findings are also in line with Kent’s (2000) model of psychosocial distress for individuals with visible difference. Kent’s model incorporates Baumeister and Leary’s (1995) social anxiety model, Goffman’s (1968) sociological model of stigma, Rumsey et al.’s (1986) social skills training model of disfigurement, Cash’s cognitive-behavioural model of disturbed body image (Cash & Grant, 1996) and suggests an appearance that is perceived by the individual as unattractive, can intensify fear of rejection and negative appearance-related cognitions which, when in the presence of social stigma, can increase social anxiety. Furthermore, the presence of social anxiety can inhibit good social skills which further perpetuates feelings of tension and awkwardness. Together these experiences increase the likelihood of avoidance of social situations, low mood and confidence.

The psychosocial interventions Kent’s model suggests - social skills training (SST) and cognitive behavioural therapy (CBT) - may offer therapeutic opportunities for this population (McBain et al., 2014). Indeed, there is increasing evidence to support the efficacy of CBT for appearance related anxiety, or a combined CBT/SST approach, for supporting adults with visible difference (Kleve et al., 2002; Norman & Moss, 2015; Williamson et al., 2015).

The anxious preoccupation with injury to and loss of sight of the healthy eye identified by participants can lead to withdrawal, depression and social anxiety in individuals with impaired vision (Binder et al., 2018; Soleimani Sefat et al., 2017; Visagie et al., 2017). Whilst previous literature highlights that depression and anxiety are under recognized and sub-optimally treated within the ophthalmic setting (Rovner et al., 2007), a few studies have shown some evidence of the effectiveness of psychosocial interventions (Nollett et al., 2016; Rovner et al., 2014; Soleimani Sefat et al., 2017; van der Aa et al., 2015). These studies are theoretically framed within Beck’s (1983) cognitive model of depression, and sought to integrate cognitive behavioural approaches, adapted for visual impairment, into rehabilitative programmes of intervention. CBT, adapted to the context of visual impairment, may therefore be an applicable psychosocial treatment to reduce vision-related anxiety and depression in this population.

The current finding that a sense of stigma continued to infiltrate intimate relationships, resulting in the covering up of the enucleation site is opposed to previous research reporting facial prosthesis wearers did not feel the need to cover up in the presence of partners and family members (Yaron et al., 2018). In this regard, therapeutic consideration of interpersonally orientated interventions where traumatic disfigurement interrupts intimate interpersonal processes may be helpfully considered (Johnson, 2002).

These findings need to be considered in light of the limitations of this study. The research was conducted at a single site and the sample size is small, although it is appropriate for a qualitative study of this nature. These two factors limit any generalisations that can be made to the wider population. Of course, generalisability is not necessarily the focus of qualitative research, but it is important to make this explicit.

In conclusion, these findings may offer healthcare professionals richer understandings of the psychosocial needs of this patient group at different stages post injury and raise considerations for the development of services and provision of psychological interventions. Future research in the area will benefit from exploring the experiences of those wearing ocular prostheses as a result of disease related processes or treatment or as a result of genetic causes of eye loss such as microphthalmia to establish whether the current findings are generalisable.

CRediT authorship contribution statement

Joni Keys: Conceptualization, data collection, analysis, writing original draft. Martin Dempster: Conceptualization, analysis, supervision, writing- original draft preparation and edits. Jonathan Jackson: Conceptualization, validation, writing – reviewing and editing. Michael Williams: Conceptualization, validation, writing – reviewing and editing. Sinead Coyle: Data curation, validation, writing- reviewing and editing.

Declaration of competing interest

The authors declare that there is no conflict of interest.

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