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Title: Wheelchair users' experiences of integrated dance in Ireland.

Abstract

Introduction: In Ireland, there are approximately 40,000 wheelchair users. For many people, an appropriate, well-designed and well-fitted wheelchair is a facilitator to increase independence, enable inclusion, occupational engagement and participation in society.

Integrated dance is a physical art form that enables wheelchair users to explore and express their creativity through dancing. Due to the dearth of scholarly research into this occupation, the aim of this research is to understand the experiences of wheelchair users who participate in integrated dance in Ireland.

Method: The methodological design for this study used a broad qualitative approach.

Purposive sampling was used to recruit two male wheelchair users who participate in integrated dance through a gatekeeper of an integrated dance company in Ireland. Individual semi-structured interviews were conducted with the participants. The transcribed interviews were analysed using thematic analysis.

Findings: Through thematic analysis three themes were identified. 'The power of assistive technology' outlined the importance of their wheelchair to enable occupational engagement. 'Confronting challenges' outlined challenges they face as wheelchair users. 'Dance as a foundation' outlined how dance has enabled the participants to explore other occupations and integrate these occupations with the dance.

Conclusion: As the findings reveal that engaging in integrated dance has many benefits, wheelchair users continue to encounter challenges. Occupational therapists are key specialists involved in providing appropriate wheelchair and seating assistive technology. This study contributes to identifying the need for a national policy for wheelchair and seating provision in Ireland to enable individuals to engage in meaningful occupations.

Introduction

A wheelchair's main function is to improve the quality of life of people with certain types of impairments that impact on mobility (Rousseau-Harrison *et al* 2012). Engagement in recreation and sport are valuable occupations to improve physical, psychological and social health benefits for individuals (Malkogeorgos *et al* 2011; Shores *et al* 2015). Integrated dance is a physical art form where people with and without disabilities engage together to explore, create and perform dance together (Benjamin 2002; Herman and Chatfield 2010; Irving and Giles 2011). Integrated dance for a wheelchair user assists with physical development, exercise and social participation (Hong *et al* 2013). A national policy for appropriate wheelchair and seating provision, "an overall term used for wheelchair design, production, supply and service delivery" (World Health Organisation [WHO] 2008 p.11), that is recognised by the WHO guidelines, is crucial to ensure wheelchair users have an equal opportunity to engage in their chosen occupations (Gowran *et al* 2012), which Ireland does not currently have. Therefore, the aim of this study is to understand the experiences of wheelchair users who participate in integrated dance in Ireland.

Literature Review

Importance of the wheelchair and seating

Assistive devices, including powered and manual wheelchairs, are used to compensate for disabilities causing difficulties with accomplishing daily tasks (Rousseau-Harrison *et al* 2009). Wheelchair and seating assistive technology provide postural support, enhance personal mobility, enable independence and improve quality of life, requirements for human rights (WHO 2008). Mobility and movement are central to individual's identities, life experiences and opportunities (Imrie 2000). A study conducted by Rousseau-Harrison *et al* (2009) found that all of the participants saw the wheelchair as a facilitator in carrying out most daily activities.

Occupational engagement

People engage in occupations to meet their individual goals to provide them with an opportunity for social participation (Wilcock 2006). In combination, doing, being and becoming are essential to health and well-being for everyone because together they characterise occupation (Wilcock 1999). A study that explored the meaning of occupational

engagement for wheelchair basketball athletes found that occupational engagement can contribute to individuals' development, which allows them to face challenges, develop skill, overcome disabilities and achieve a meaningful goal (Garci and Mandich 2005). Little research has focused on wheelchair users, despite recognizing that this population can benefit from exercise (Froehlich-Grobe *et al* 2012).

Integrated dance

In recent years there has been a shift in the way disability is perceived around the world; studies conducted over the past decade have indicated an increase in integrated leisure, sport and recreation (Irving and Giles 2011). There has been a positive shift towards recognising the contribution to dance by disabled performers (Whatley 2007). Dance comprises technical training of the dancer's body (Albright 1997). Dance can be inspiring, rewarding and challenging for people with disabilities (Aujla and Redding 2013). In a Cochrane review of people with spinal cord injuries who participated in wheelchair-adapted Ballroom/Latin dancing, participants demonstrated significant improvements in strength, wheelchair skills, upper extremity coordination and social participation (Hong *et al* 2013). In the absence of occupation, individuals can struggle with identity loss, which therefore sacrifices the integrity of their well-being (Stone 2003). To promote dance as an occupation for wheelchair users, it is necessary to understand the challenges they could face in their quest for dance including attitudinal, training-related, building access and logistical barriers (Aujla and Redding 2013).

There is a lack of scholarly work that focuses on integrated dance (Irving and Giles 2011), or on the experiences of wheelchair users who engage in dance (Goodwin *et al* 2004), particularly in Ireland. The literature has recognised the importance of the wheelchair and seating to enable occupational engagement. Therefore, the focus of this study is to understand the experiences of wheelchair users who participate in integrated dance.

Methods

Research Design

This study is part of a larger study 'Exploring occupational engagement in wheelchair sports and recreation to enhance physical activity'. Critical theory is the overarching paradigm that guides this research. Its concepts aim to liberate individuals, illuminate power relations and reveal the ideologies that shape people's lives (Carpenter and Suto 2008). The methodological design for this study used a broad qualitative approach. Qualitative methods

provide occupational therapy researchers with ways of exploring clients' beliefs and the meanings from their experiences (Hammell and Carpenter 2000; Yin 2010; Creswell 2013).

Participants

Two male wheelchair users, over 18 years old, with diagnoses of cerebral palsy were recruited through a gatekeeper of an integrated dance company in Ireland. Both met the inclusion criteria; adult wheelchair users who participate in integrated dance. The small number of participants were recruited through purposive sampling which enables in-depth understanding of their personal experience who can provide the most relevant information regarding the topic (Mayan 2009; Patton 2014). The aim was to recruit 10 participants through observation of the dance classes, however, due to cuts in funding, activities in the company had to cease; therefore observations could not proceed. A recruitment email was sent to the gatekeeper who forwarded it on to potential participants and subsequently followed with a phone-call. Following expressed interest, phone-calls were made between the researcher and participants to schedule the interviews.

Data Collection

Data was gathered using a semi-structured interview guide provided by the supervisor. It was derived from influences of Kronenburg *et al* (2005) political reasoning tool and Capra (2003) reflective consciousness which considers participants experiences of being involved in the wheelchair and seating services. Semi-structured interviews allow the researcher to build rapport and conduct the interview in a flexible way (Stein *et al* 2013). The one-to-one interviews were conducted at a time and place convenient for the participants. The interviews lasted between 40-45 minutes. The interviews were recorded with a digital recorder and the data from the interviews were transcribed verbatim, using pseudonyms to protect confidentiality and anonymity (Carpenter and Suto 2008).

Data Analysis

Detailed checking of the transcripts against the audio recordings enabled familiarity with the data. Thematic analysis was used to interpret the participants' experiences and to identify themes. This approach does not require in-depth experience which also allows highlighting of similarities and differences across data and can also generate unanticipated insights (Braun and Clarke 2006). The data was analysed using the six stages (see table 2). The transcripts

were analysed manually due to the small-scale study, as it provides the researcher with management and ownership of the work (Saldaña 2015).

Table 2. Braun and Clarke’s (2006) phases of thematic analysis.

Phase	Description of the process
1. Familiarisation	Transcribe, read and re-read data, note down initial ideas.
2. Generate initial codes	Systematically code data; collate data relevant to each code.
3. Search for themes	Collate codes into potential themes.
4. Review themes	Check if the themes work in relation to the coded extracts and entire data set.
5. Define and name	On-going analysis to refine the themes and the overall story of analysis, generate names for each theme.
6. Produce the report	Select vivid, compelling extract examples, final analysis of extracts, relate analysis back to the research question.

Reflexivity

Reflexivity requires the researcher to reflect on all aspects of the research process. The researcher ensured reflexivity by writing field notes following completion of the interviews (Carpenter and Suto 2008). A reflexive diary was used in an effort to ensure that the findings were reflective of the participants’ rather than the researcher’s perspectives (Finlay 1998; Curtin and Fossey 2007).

Trustworthiness

To ensure trustworthiness four criteria should be considered when conducting qualitative research (Lincoln and Guba 1985). Credibility is established through the authentic representation of the participants’ experiences by using quotations from the transcribed data (Carpenter and Suto 2008). Transferability connects to the existing universal literature which can be applied any country (Carpenter and Suto 2008). Dependability and confirmability are achieved by providing a clear description of how the data has been collected and analysed (Uzzell and Barnett 2006).

Ethical Considerations

Ethical approval was obtained from the University of Limerick Faculty of Education and Health Sciences Research Ethics Committee; Reference: 2015 04 23 EHS. Participants were provided with an information sheet inclusive of their right to withdraw at any time during the interview or research process, without repercussions, until the data was analysed. They were informed that due to the small community involved in this area complete anonymity is not guaranteed. A consent form was explained verbally to the participants by the researcher to ensure they understood its content before consenting to participate. Each participant signed the consent form prior to commencing the interview.

Findings

Thematic analysis of the data generated three themes of the participants' experiences as wheelchair users who participate in integrated dance. They include: the power of assistive technology, confronting challenges and dance as a foundation. The content of each one are revealed using quotations from the interviews.

Theme 1: The power of assistive technology

A key theme that emerged from the interviews was the importance of the wheelchair to enable occupational engagement. The participants engage in various occupations including dance, education, sport, poetry, music, art and film making. The participants described what the wheelchair means to them.

...that's your, your life like, that's your legs... my legs don't work...so I say my wheelchair is my legs. (John)

Both participants identified how the wheelchair assists them with pain relief. Adjusting the wheelchair to a different position can ease the pain either daily or while dancing.

... what I use on my day-to-day running and my day-to-day activities is a power wheelchair...it can tilt so if I get pain, if my muscles get sore, the wheelchair—I have a button on the wheelchair that will tilt up like a bed to give me a rest for the muscles and when you tilt the wheelchair, that's like walking. It's taking the weight off and it kind of—I'm not moving in the wheelchair but by tilting, you're moving your legs into a different position. (William)

Both participants described how their wheelchairs were used while participating in the integrated dance classes. They identified how the wheelchairs assisted with creativity and how it added value to the dance.

And I also have the lighting indicator on the wheelchair so when I'm dancing, it kind of—if we need any lighting, or we need a bit of light, it might be handy to turn on the light when I'm dancing. (William)

John demonstrated the wheelchair rising up and tilting back during the interview.

I used to do dance movements like this and my partner used to lean over me and stuff like that... and then it goes up like this... it used to make the dance look good. (John)

The participants spoke about how their wheelchair provides them with comfort and that it enables them to be independent.

It's very good because you can—I just know this, you can do so much in a wheelchair. (William)

John is awaiting a new wheelchair, which will provide him with greater independence. It will be compact and will provide him with more space to engage in daily activities.

Yeah so the good news is with the new wheelchair hopefully I won't need half these controls cos I can work everything from the chair. There is a—at the side of the tray, do ya see all the controls I have here, they work everything, television, stereo. So I can do away with all these controls so I'll have more space on my tray... for a cup of coffee or a glass of wine or whatever. (John)

Theme 2: Confronting challenges

A second theme that emerged from the interviews included various challenges that the participants encounter as wheelchair users. Both participants experienced challenges in the process of receiving a new wheelchair. They both discussed how long they had the one wheelchair. They both identified that what is meant to happen and what does happen are very different when it comes to the process of receiving a new wheelchair.

William was waiting eight years for his current wheelchair from the time it was ordered until he received it in 2015.

I was going around in a power wheelchair for 14 years. (William)

Similarly, John revealed the age of his current wheelchair. He has been waiting two years to receive a new wheelchair.

It's about... 12 or 11 years old at this stage. (John)

Both participants described challenges they encounter regarding the integrated dance. Along with needing a driver to get to the classes, John faced challenges accessing facilities.

Some bathrooms you can't even close the door, like, it's crazy...because, I've to take in the wheelchair to the bathroom and it's not even this wheelchair it's my mobile wheelchair, I go out in for that very reason...cos it's smaller...and you can't even close the door even in the mobile one, or even, the manual wheelchair... even though they passed the regulations... (John)

Both men spoke about challenges during the dance classes. Pain and exhaustion were identified as challenges. William described a situation where he was challenged but through determination he could succeed.

Yeah, what I don't like is, it's good but, if we're making a video, we have to take the camera shot over and over again. And it's really, it's really hard and then another one is when the camera man is taking different angles. You have to move your body up and you have to hold it there and you might get pain but you're holding it and it's in your mind, I can do this. (William)

Both interviews identified the need for disability awareness to be addressed.

And I don't think there's enough about disability awareness, at a wider level... if only people could go and talk in local shopping centres and something like that... we've come a long way, but we've a long way to come yet... (John)

In terms of integrated dance, William also acknowledged the fact that increased awareness is a necessity to expand the awareness of integrated dance.

More people with disabilities to get involved, or not even with disabilities, more people without disabilities to get involved, to help. (William)

The participants discussed challenges they face as wheelchair users. When governmental bodies let them down, it prevents them from participating in everyday activities. At times, they need to rely on others when challenges like these arise.

I've a PA but I don't have any social hours for a PA...so that's a bit of a pity really. Especially when you're stuck out here... I mean, I have PA for assistance but I have no social hours...but do you know sometimes you get tired of fighting...you get so tired of it. And I don't give up easily but there's sometimes you're fighting for everything together and you get so tired of it. (John)

When his wheelchair broke down, William was without it for an entire weekend while it was being repaired.

I was just mad about other people who, who really need the wheelchair. The wheelchair is their life... the wheelchair is incredible but I just wish that the HSE did more for people with wheelchairs. (William)

Theme 3: Dance as a foundation

A third theme that emerged from the interviews was how dance has enabled the participants to explore other occupations and integrate these occupations with the dance. The participants spoke about their positive experiences of being involved in integrated dance. Both participants exercise outside of participating in the integrated dance. Therefore, it can assist with their endurance. Although dancing can be fatiguing, the participants acknowledged the physical benefits of participating in integrated dance.

You feel great. You feel happy and you feel it's helping your body because for me I can walk a bit and for me dancing it's using all my muscles and you work the muscles that you never worked before. So in my wheelchair, when I do movements you're working your muscles that you wouldn't work before. So it's gaining, it's a gain for me dancing because it's the best thing. (William)

The participants described how the integrated dance enables them to be creative and express themselves. Both participants provided examples of the other occupations they engage in.

I write poetry and I kind of combine my poetry into integrated dance...the poetry for me it makes the dance. It kind of—dancing is like acting, your acting through dancing. (William)

A common occupation that both men expressed interest in was being involved in making films of the dancing. They described what aspects they enjoyed.

...I'm still involved in dancing in so far as I still do the films so I'm still very much involved... I'm interested and I love it and all of that and I'm mad about the film side of it now. (John)

Both men acknowledged that they enjoy the social aspect of the integrated dance. William enjoys the live performances.

Making videos, putting on shows is the best thing ever...performing in front of people is the best thing ever. (William)

Both participants identified the benefits of integrated dance as it has led to engaging in other occupations.

...if I didn't start off as a dancer I wouldn't have known anything about dance film... (John)

Also evident from the interviews was the determination of both participants and how being in a wheelchair did not stop them from engaging in the occupations they were passionate about.

...it's amazing what you can do when you have a disability or in a wheelchair. In my head, just because you're in a wheelchair, don't hold back from what you want to do. (William)

Discussion

The analysis generated three themes related to the experiences of the wheelchair users. 'The power of assistive technology' outlined the importance of their wheelchair to enable occupational engagement. 'Confronting challenges' outlined challenges the participants face as wheelchair users. 'Dance as a foundation' outlined how dance has enabled the participants to explore other occupations and integrate these occupations with the dance. Both participants identified the importance of having an appropriate wheelchair to enable engagement in occupations. Using a wheelchair does not stop them from engaging in occupations; it enables them to express themselves. These findings mirror Goodwin *et al* (2004) and Irving and Giles (2011) findings from an outsider's perspective, the wheelchair can be viewed as a symbol of weakness and dependence however, from the dancers' perspective it provided a means for emotional, creative and physical freedom. The findings highlight that occupational engagement can contribute to enabling the individuals to overcome disabilities and achieve meaningful goals, which has also been established with wheelchair basketball athletes (Garci

and Mandich 2005). The findings suggest that the wheelchair is part of their embodied existence, which echoes Papadimitriou (2008) exploration of becoming en-wheeled after a spinal cord injury.

The appropriate provision of a wheelchair is essential to meet the needs of users through enabling independence and enabling active participation as a basic human right (WHO 2008). Barriers were identified by the participants which resonate with the literature. These interruptions to engagement and barriers to participation are known as occupational disruption and occupational deprivation (Wilcock 2006). The findings revealed that an inappropriate wheelchair can be a barrier to participating in meaningful activities, which mirrors a study of 70 wheelchair users that found the wheelchair was the main barrier to participation either at home, during transportation and the community (Chaves *et al* 2004).

Resonating with the findings, environmental requirements for parking and entrances are generally met however, access can be poorer to bathrooms (Nary *et al* 2000). Logistic barriers to dance training include transport, care and support needs therefore, financial costs are often implicated in all of these factors (Verrent 2007). As the findings discovered pain was reduced through the use of the wheelchair, it echoes a study with 45 mobility technology users that found wheelchairs decreased pain and improved pain management (Hammell *et al* 2013).

As the participants identified that disability awareness is a necessity at a wider level, it was also suggested in terms of how awareness would be beneficial regarding integrated dance. This is reflected in the literature, in that dance providers should offer disability awareness training and specific teacher training in integrated practice for their staff (Aujla and Redding 2013). Non-disabled individuals would also benefit from disability awareness training (Whatley 2007) to gain confidence in engaging in the integrated classes and to assist with the future generation of dance artists in being aware of inclusion and access issues (Aujla and Redding 2013). The 'Convention on the Rights of Persons with Disabilities' is intended to promote, protect and ensure equal enjoyment of all human rights by persons with disabilities (United Nations 2006), however this is not evident when accessibility issues encounter wheelchair users, which were discussed by the participants. This is also echoed in a systematic review where a barrier to social participation involves the physical access to buildings and certain areas of the venue (Jaarsma *et al* 2014). As both participants identified the enjoyment of social interaction while participating in integrated dance, the barriers may

impact on their rights. Studies have also revealed that wheelchair users found that participation in team sports influenced the social interactions of the students who were involved (Garci and Mandich 2005; Wessel *et al* 2011).

The findings revealed that the participants could be creative and express themselves with the use of their wheelchair through different movements. This is echoed in Goodwin *et al* (2004) exploration to understand the lived experiences of children who were members of a wheelchair dance programme. It was found that where the wheelchair was a provider to move independently, its' practical function was developed to a greater understanding, as it enabled creativity and personal expression, an expansion from its utilitarian function (Goodwin *et al* 2004).

Participation in daily occupations provide individuals with opportunities to enhance their quality of life and influence their health and well-being (Polatajko 1994; Wilcock 2006). Occupation provides meaning to an individual's life as it can accomplish a purpose, provide structure, support with coping with change and empower the individual (Townsend and Brintnell 1997). These statements are reaffirmed by the final theme which reveals the significance of how dance has enabled the participants to explore other occupations and integrate these occupations with the dance. It was apparent that occupations are part of their identity. Through occupational engagement individuals develop and maintain health and happiness (Baum and Law 1998), and defines personal identity while giving meaning to life (Christiansen 1999).

Limitations

It is acknowledged that several limitations were present, most notably the small sample size. As previously mentioned the anticipated plan could not proceed due to cuts in funding and consequently cessation of activities in the dance company ensued. Due to the funding constraints, occupational injustice is portrayed here as participation in occupations have been restricted (Townsend and Wilcock 2004).

Further methods to recruit additional wheelchair users were attempted including snowball sampling (Goodman 1961), through the initial participants, however this was unsuccessful. Contact was also made with an alternative organisation, however due to time limitations, ethics would not have been received in due time. Alternative methodologies including

biographical accounts and auto-ethnography (Alasuutari *et al* 2008) were explored however, these were not deemed suitable with the interviews.

Due to the small sample size, the interpretation of the findings should be made with caution. The study was limited in regard to gender, with no female wheelchair users participating in the study. A mix of gender within the sample may produce more varied findings. The findings of this study cannot be generalised as they only reflect the experiences of wheelchair users from one geographical region. Member checking could have been employed by sending the participants a summary of the findings to ensure they were reflective of their experiences (Bryman 2012); however, owing to time limitations it was not possible. The researcher's inexperience of conducting this type of research must also be considered as a limitation in the study.

Implications for Professional Practice

In Ireland, there is no evident route for evaluation of appropriate wheelchair and seating provision from accessibility of services through to assessment, prescription, follow-up and management (Kane 2000). Occupational therapists are one of the specialists involved in providing people with appropriate wheelchair and seating assistive technology (WHO 2008). As gatekeepers to wheelchair and seating provision, occupational therapists need to evaluate the role they play in providing appropriate wheelchairs and acceptable service delivery and follow-up (Kenny and Gowran 2014). A clear finding for occupational therapists is how occupational engagement for wheelchair users contributes to achieving meaningful goals. As inappropriate wheelchair and seating provision can have devastating physical effects (Arthanat and Strobel 2006) with financial and emotional implications (Batavia *et al* 2001), it is essential for occupational therapists to be aware of the detrimental impact these implications can have on occupational engagement.

As there is a dearth of scholarly work on the experiences of wheelchair users who participate in integrated dance in Ireland, occupational therapists may not be familiar with this occupation. It is essential that occupational therapists have a clear understanding of the importance of the correct wheelchair for individuals that engage in integrated dance and other meaningful occupations. As people with disabilities are more likely to experience a sedentary lifestyle than the general population (Bodde and Seo 2009; Barfield and Malone 2013); it can be due to several barriers (Rimmer *et al* 2004). The findings identify the challenges that wheelchair users encounter, therefore, occupational therapists must be aware of these to assist

with enabling their client to engage in occupations of their choice. As the findings suggest, disability awareness is a necessity and a role in which occupational therapists play a part in.

Recommendations

Occupational therapists can use these findings when working with wheelchair users as an alternative form of physical activity which individuals may not be familiar with. These findings may contribute to the Healthy Ireland Framework Government action plan (Department of Health 2013), that was published to support health and wellbeing of people in Ireland, with physical activity as a main element, however with limited strategies identified for people with disabilities. To enhance this study, further qualitative studies are required with larger sample sizes to strengthen or challenge the findings of this study. Experiences of wheelchair users with alternative disabilities could be researched to identify if they experience the same physical effects and challenges. Locating gatekeepers and accessing other dance organisations around Ireland would heighten the probability of recruiting more dancers. Future research could address the experiences from a female population. As this research was solely completed with adults, the experiences of children could be explored. It is also recommended that an observation of integrated dance is completed along with interviews to enhance the findings of future studies. Research with alternative methodologies may also contribute to knowledge of integrated dance.

Conclusion

In adopting a qualitative approach, this study has explored the experiences of wheelchair users who participate in integrated dance in Ireland. The analysis generated three themes related to the experiences of the wheelchair users. ‘The power of assistive technology’ outlined the importance of their wheelchair to enable occupational engagement. ‘Confronting challenges’ outlined challenges they face as people with disabilities. ‘Dance as a foundation’ outlined how dance has enabled the participants to explore other occupations and integrate these occupations with the dance. Although the findings reveal that engaging in integrated dance has many benefits, there are also challenges wheelchair users encounter. It was evident from the findings that disability awareness is a necessity for the future, and an area in which occupational therapists must continue to advocate for. Occupational therapists are key specialists involved in providing appropriate wheelchair and seating assistive technology. Although further research is recommended, this study contributes to identifying the need for a

national policy for wheelchair and seating provision in Ireland to enable individuals to engage in meaningful occupations.

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