How older men with disabilities navigate stigma to maintain social networks: A qualitative study.

Abstract

Introduction: The experience of stigma is a significant societal barrier faced by many people with a disability; it is not well known how people navigate stigma in order to establish and maintain friendships. Social participation is an occupation which enhances a person’s well-being and quality of life, however, opportunities for social engagement can diminish as a person ages. This study aimed to explore how older men with a disability in Ireland navigate disability-related stigma to create and sustain lasting friendships.

Method: The study was guided by critical disability theory. A qualitative approach, influenced by ethnographic principles, was applied through semi-structured interviews. The dataset for this study included 12 men aged 50-70 years with varied disability experiences. The data was analysed thematically using Atlas.ti software.

Results: Participants demonstrated a breadth of experience in navigating stigma associated with their disability in order to create and sustain friendships. Three main themes emerged from the data: ‘community involvement’, ‘shared interests’ and ‘peer relationships’.

Conclusion: This paper contributes to the limited knowledge of how older men with a disability in Ireland access friendships in their communities and emphasises the importance of meaningful occupation and peer support. This study indicates that older men can be a source of support for one another as they navigate their individual disabilities and strive to create and sustain their social networks. The findings provide a new insight for occupational therapists of their role in promoting social engagement through the facilitation of occupation-focused peer groups.

Keywords; stigma, disability, friendship, ageing, social participation.
Introduction

As the population ages, the number of older people with a disability is increasing (Central Statistics Office 2011). According to results from the Survey of Attitudes to Disability in Ireland (National Disability Authority 2011), negative attitudes towards those with a disability exist amongst the general public. Current research fails to examine how these negative attitudes affect how older men develop and sustain friendships within their communities.

Disability and stigma:
Stigma is a social process (Goffman 1963; Young et al 2013), experienced through exclusion, devaluation, blame and rejection (Scrambler 2009; Buljevac et al 2012). Stigma has been defined through the actions of labelling, stereotyping, separation, status loss and discrimination (Link and Phelan 2001). The International Classification of Functioning (ICF) suggested that negative social attitudes are one of the most disabling factors for people with a disability (WHO 2001). Many disabilities have been examined in relation to their stigmatising effects including; Parkinson’s disease (Hermanns 2013), addiction (Earnshaw et al 2013; Hill and Leeming 2014), depression (McLoughin 2013), intellectual disability (Abraham et al 2002; Patterson et al 2012; Walker and Scior 2013) and mental illness (Goldberg 2003; Putnam 2008; Wood et al 2014). Disability-related stigma has negative consequences on health and well-being (Young et al 2013) and negatively affects people realising their wishes to be socially included (Buljevac et al 2012).

Friendship:
Friendship is important for giving people a sense of belonging. The continuity of friendship, shared history and similar values between friends help enhance self-identity (Northcott and Hilari 2011). Friendships boost self-esteem and increase feelings of usefulness, while socialising and forming strong bonds with others increase overall wellbeing (Greif 2009). Men often base their friendships around activities and doing (Migliaccio 2010). They are more likely to engage in comradeship in groups over one-one friendship (Levy 2005) and have a strong sense of fraternity and loyalty to their chosen group of friends (Butera 2008).
It is important to consider how life events that typically occur for men in middle to late adulthood; widowhood, bereavement, divorce, retirement and moving house can all greatly impact on friendships (Alpass and Neville 2003; Shaw et al 2014). It has been established that people with a disability tend to have smaller social networks (Harley et al 2012) and struggle to affirm their identity within social circles (Grytten and Maseide 2006). However, little is known about how men with a disability experience friendship at the middle to late adulthood life stage.

Summary
Stigma has a very real and negative effect on the social health of people with disabilities. Studies exist which have explored the effect of stigma on the development and sustainment of friendships, for people with a particular disability. There is a lack of research on disability across the spectrum, as well as a lack of age-specific and gender-specific studies. Therefore this study will explore how Irish men aged 50-70 years, with varying disabilities, navigate stigma to create meaningful and lasting friendships in their communities. The objective of this research is to map out strategies that men apply in order to achieve this.

Method:

Research design
The researcher’s paradigm of enquiry was informed by critical disability theory. A critical approach to disability studies came about through calls to have a more contemporary approach to conceptualising modern day theories and politics in relation to disability (Nussbaum 2007). The purpose is to understand an occurrence in the social world and to empower marginalised groups of people (Goodley 2013). A qualitative approach was taken as the research explores an aspect of the lives of people with a disability (Silverman 2008, Creswell 2013). The study was guided by ethnographic principles as it was investigating a community of people (Atkinson et al 2007).

Sampling and recruitment
This research study was part of a larger project where data was collected and analysed over three years (2012-2015) by a principal researcher, another experienced researcher and a number of MSc Occupational Therapy students. Prior to recruitment ethical approval was
granted from the University of Limerick’s Education and Health Sciences Research Ethics Committee (approval number EHSREC11-35). There were many ethical challenges to consider for example consent and confidentiality. Consent to participation is an on-going process (Silverman 2008). In the recruitment stage participants read an information letter (Bjorn et al 1999; Allmark 2002) and signed a consent form or an accessible consent form, depending on literacy levels, before engaging in the interview process. These papers followed National Adult Literacy Agency (NALA) guidelines for accessibility of text. Confidentiality was upheld as participant numbers were allocated to all those in the larger study.

The initial researchers recruited participants through convenience sampling, whereby they approached accessible sites (Marshall and Rossman 2011). Information sessions were held at various mental health services, primary care centres and local health offices. Potential participants, support staff and family members were invited to attend these sessions where an information letter and a research poster were provided. There were certain inclusion and exclusion criteria to be adhered to as purposive sampling allows a researcher to select participants who will address the research question (Creswell 2013). This also ensured there was a range of disabilities represented. The larger project had 93 participants in total, from many locations around Ireland, with varied disability experiences. Table 1 displays the dataset for the 12 men in this study.

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Participant Age</th>
<th>Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>93</td>
<td>60’s</td>
<td>Anxiety and depression</td>
</tr>
<tr>
<td>19</td>
<td>50-59</td>
<td>Wheel-chair user</td>
</tr>
<tr>
<td>89</td>
<td>52</td>
<td>Multiple Sclerosis</td>
</tr>
<tr>
<td>57</td>
<td>54</td>
<td>Intellectual Disability</td>
</tr>
<tr>
<td>68</td>
<td>65</td>
<td>Depression</td>
</tr>
<tr>
<td>69</td>
<td>Early 50’s</td>
<td>Depression</td>
</tr>
<tr>
<td>74</td>
<td>63</td>
<td>Back Injury</td>
</tr>
<tr>
<td>79</td>
<td>52</td>
<td>Intellectual Disability</td>
</tr>
<tr>
<td>82</td>
<td>53</td>
<td>Back Injury</td>
</tr>
<tr>
<td>85</td>
<td>68</td>
<td>Guillian Barre</td>
</tr>
<tr>
<td>49</td>
<td>52</td>
<td>Multiple Sclerosis</td>
</tr>
<tr>
<td>90</td>
<td>53</td>
<td>Addiction, depression and psychosis</td>
</tr>
</tbody>
</table>

Data collection

The data was obtained through semi-structured open-ended interviews; this style of interviewing encouraged participants to speak freely whilst also allowing interviewers to gently guide the topics discussed; which is conducive to obtaining a range and breadth of
subject matter (Silverman 2011). All interviews had fieldnotes attached that were completed by the original interviewers. These fieldnotes described the context in which the interview took place and the interviewer’s initial impressions. The fieldworker is engaged in preliminary analysis in this stage (Lofland 2006). These notes were available for the current researcher to consider.

Data analysis
In the existing dataset investigated, two interviews remained to be transcribed and five of the 12 transcripts were coded. The remaining interviews were transcribed and all 12 transcripts were analysed and coded. The data was analysed thematically using Braun and Clarke’s (2006) flexible approach. This provided a detailed and compound account of data and is viewed as the first method a researcher should learn as it provides core skills for conducting analysis (Braun and Clarke 2006). Working with the existing coding list, this researcher layered onto coding; using their own perspective. Braun and Clarke’s stages of analysis were followed by; reading the clean transcripts and becoming familiar with the data, searching for themes by highlighting key ideas and seeing how they connected. The researcher then defined and named the ideas and distinguished them from each other and finished by producing a concept map which developed into a findings report.

Reflexivity in research can be achieved through the researcher examining their own background, their assumptions and relationships with the researched (Finlay and Gough 2003; Dowling 2006). As a Registered Intellectual Disability Nurse and a MSc Occupational Therapy student, the researcher’s keen interest in the disability experience was recognised. Any personal reactions to reading transcripts were discussed with research peers. The student researcher debriefed with peers and the principal researcher regularly throughout the process of this project as an action to improve credibility and transparency (Zarin and Tse 2008). Atlas.ti was used to complete thematic analysis; this improved confirmability by connecting the data to the source (Malterud 2001). Initial findings were presented to student peers for feedback and this helped formulate the structure and presentation of results. All of the above enhanced the overall trustworthiness of the research (Graneheim and Lundman 2004).

Dependability (Glasgow et al 2005) was enhanced as there were many researchers working on this project, all bringing their own perspectives and checking over coding. As well as completing their own coding, the student viewed previous student’s work also. Analytical decisions were recorded systematically and consistently throughout data analysis through the
‘memos’ feature in Atlas.ti. The large number of researchers and research students coding the data verifies the appropriateness of the allocated codes.

**Results**

Participants demonstrated a breadth of experience with navigating disability-related stigma in order to create and sustain friendships. Three broad themes emerged from the analysis; ‘community involvement’, ‘shared interests’, and ‘peer relationships’.

*Community involvement*

For many participants, being involved with community projects and events as well as having close connections with their neighbours was a positive approach to sustaining friendships and long term relationships. All participants had social networks where they lived.

For example, P49 was involved with the Gaelic Athletics Association (G.A.A), which helped him remain linked with community events and news. However, he became uncomfortable with attending matches due to his progressing disability. This was an important social venue for him so he navigated around the problem by staying involved with the G.AA club through an administrative role and thus remained a supporter and a valued community member.

Similarly, P82 was involved with the GAA for a long period of time. He made many friends through his local club and remained involved as his children continued to play. It appeared that having his children grow up in the same locality and be involved in the same hobbies helped him plant roots firmly in the community, which was a great source of support for him.

He valued keeping in touch with his same group of friends. “I’d still be within the circle of people I know” (P82). For this gentleman, sustaining his connections with the G.A.A. helped him to maintain his social network. P85 sustained his connections with his community in a different way. He was heavily involved with volunteering in his locality and this was something that gave him great joy, as well as a sense of belonging and achievement. He felt valued in his contribution to his local community.

Many other participants spoke about the importance of socialising with neighbours and chatting over tea in each other’s houses; as illustrated by P90; “I love when he comes in because we go back a long way” (P90). This was the case for a number of participants who stated that visiting neighbours was an important way to stay connected with local news and events.

0764345
For P74, his religious faith was very important to him and this influenced his approach to community involvement. He attended his local church and this was a social occasion for him; as he had the opportunity to interact with his neighbours. He emphasised that it was important to him to continue this practice as a religious and as a social event.

Participants demonstrated a variety of ways in which they used community involvement, through the G.A.A, volunteering, visiting neighbours and religious practice, as a strategy to stay connected to their social networks.

**Shared interests**
Taking part in activities and pursuits that were meaningful to the participants appeared to be an effective way to connect with others. It was clear that a shared interest was an important foundation for friendship to develop and seemed to be a vital aspect in sustaining friendships also.

P19, who acquired his disability later in life, described how he initially distanced himself from socialising with other wheelchair users for fear of others labelling him or making assumptions about his disability. Over time this fear of stigma by association dissipated. He developed friendships with people who were wheelchair users but he stressed that the friendships were formed on mutual hobbies and shared interests rather than a shared disability.

“It just so happens I have friends who are wheelchair users. Did I pick them because they are wheelchair users? No. Like one of my best friends has a spinal injury the same as myself and we kayak together so that’s how we became friends not because of the disability but rather the fact that we both kayak” (P19).

P19 explained that this shared interest was more important to him than a shared diagnosis in the context of friendships.
Likewise, P82 explained the importance of sharing interests with friends. He described his relationship with his close friend with whom he had an established friendship. They were both farmers and they both loved reading novels. They often gave books to each other on loan and enjoyed discussing them together. Similarly, P89 described a friendship he had with
another man with a disability who lives in his locality. He stated that they have many shared
interests and values; they were both farmers and they visited each other’s farms, offering
advice and guidance to each other. P89 described it as a mutually beneficial friendship as
they helped each other out and enjoyed each other’s company. “I do the driving, he buys the
coffee” (P89). This participant highlighted that having a disability in common is not enough
to form a friendship; people must have common or shared interests.
While P68 agreed with the importance of shared interests he had a unique experience.
Meeting an occupational therapist in the mental health facility that he attended led him to
engage in group activities which he stated increased his social network. By participating in
occupation-based groups that were appealing to him; this opened up a new way to meet
people who had similar interests.
P85 explained how he reconnected with his friends, following a lengthy hospital stay, by
participating in the shared interest of attending a pub with his friends. Following his return
home, he enjoyed visiting the pub to chat with friends which was an established social
activity for him.

“I’d go have a few pints and meet the people that I always
used to meet” (P85)

Returning to previous occupations that he enjoyed with friends was a method of re-
connecting with social networks following his illness.
In contrast to other participants who maintained social networks through engaging in shared
interests, P90 felt the need to distance himself from certain activities in order to achieve
better health and wellness. For this gentleman, recovering from addiction led to losing some
friends as he detached from certain activities and venues. Disengaging from an unhealthy
behaviour as part of his recovery from addiction led to a decrease in his social networks;
however this was a positive shift for P90.

Overall, ‘shared interests’ was an important factor that needed to be present in order to
develop and sustain friendships, as demonstrated by a number of participants.
Peer relationships

A peer relationship in this context refers to relationships with others with a disability. It was very important to participants to talk to others who understood what it was like to have a disability and to talk about disability-related issues. For most participants in this study peer support was a widely used approach to create friendships; almost all participants spoke about their involvement in peer support organisations.

P93 described the peer support group that he attended as a safe, supportive environment; he stated that people in the group were non-judgemental and he felt comfortable to seek support and share his experience. He believed peer support for people with mental health challenges was vital as there was stigma attached to mental illness in the community and people needed a safe, welcoming environment so they could talk, share and not feel judged. P93 stated that; "In a peer support centre everybody is in the same boat" (P93). It appeared that there was a sense of comradery associated with being involved with a peer support group.

Some participants spoke in detail about attending peer support groups as a means of connecting with others and combatting isolation. These participants enjoyed the social aspects of peer support, as illustrated in this comment by P79: "As long as I’m with my friends that’s all that matters to me" (P79). This was important as some participants described their involvement in peer organisations as their main social outlet.

P89 spoke about a swimming club he participated in along with other men who have a physical disability. He spoke about the personal importance of engaging in sporting pursuits with peers, as they were more understanding of the challenges people may have and supported each other. "You’re dealing with people on the same level" (P89). This idea of an equal playing field was important to P89 as ‘ordinary’ sporting groups made him feel different and highlighted deficits. He stated that while it is vital to strengthen connections between people with disabilities and people without, it is also important not to forget the value in peer support relationships.

“When you’re working with your peers like
that everybody understands what the situation is, some days you’ll be good some days you’ll be bad…..but if I go into an ordinary gym, and I’ve done it a few times…..I literally walk out crying because it just brings it home to me how bad
P89 found great advantages to undertaking leisure pursuits with his peers exclusively; he felt a sense of comradery with the other men and avoided personal comparisons with non-disabled people. The following statement by P57 adds weight to the concept of peer relationships being superior to relationships with non-disabled people.

“If they have a disability they understand each other better than the person with no disability” (P57).

This gentleman believed that people with a disability should have relationships with others with a disability as they can understand each other’s experiences better and support each other. P93 moved on from participating in the peer support groups to becoming a mentor in a mental health centre for other people accessing the service. This gentleman learned a lot from his own experiences and he wanted to share his story to help other people. Mentoring in the centre opened up connections for him and he formed friendships through this work and described feeling comfortable in this setting. Similarly, P57 spoke about mentoring younger people in the centre that he attended. He spoke about giving advice to the younger men and stated that they view him as a father figure. P57 appeared to relish this role.

“They come to me cause I’m older than them. If they have any problems I talk to them and advise them…….the elder lemon they call me” (P57).

This participant appeared to take pride in being the ‘elder lemon’ for younger men in the centre. He was looked up to and respected and this gave him a valued role in the setting. It was evident from the different accounts that older men can be a source of support, wisdom and strength for one another as they navigate their individual disabilities and strive to create and sustain their social networks. At first glance there appears to be a juxtaposition between maintaining social engagement with the wider community, through shared roles and occupations, and on the other hand a need to develop and maintain relationships exclusively
with those who also have a disability. It is clear from these findings that there is a need to have a balance of the two.

Discussion

Participants demonstrated a breadth of experience in navigating stigma in order to create and sustain friendships. The main themes which emerged from the data were ‘community involvement’, ‘shared interests’ and ‘peer relationships’.

It appeared that a having a sense of belonging through strong social connections within their communities was highly valued by participants. Each participant had different ways of involving themselves in their communities. Hammel et al (2008) discovered that social participation is very individual in how it is attributed value. Active engagement in society is individual to everyone; it was evident in this study how the individual men had different importance placed on what was a valued social event for them. In a profession that has an ethos of client-centeredness at its core (McColl 2003), it is paramount for an occupational therapist to explore what meaningful community engagement means for an individual client.

From the men’s accounts it seems that older men with disabilities should be encouraged to continue to contribute to their communities and remain actively involved in their local areas in a way in which is meaningful for them. This will help them to navigate the risk of marginalisation through stigmatisation resulting from their disability. This promotion of engagement by older people is in line with the National Positive Ageing Strategy (2013). For people with disabilities, engaging in their communities could challenge attitudinal stigma regarding the ability of older people with disabilities. This effort to challenge stigma or mitigate marginalisation is in keeping with findings by Low (1996) and Kennedy (2009).

MacKay (2006) endorsed the social mixing of people with disabilities and non-disabled people. While this was echoed in the participants desire to be involved in their local communities at an equal level as the non-disabled, there was also a strong desire by the men to spend time with people who share the disability experience. The policy of inclusion (WHO 2001; Department of Social Protection 2007) does not account for disabled people choosing to engage with other disabled people exclusively. This was evident with P89 who preferred to exercise with others with a physical disability and actively avoid exercising with non-disabled people.
Peer support for people with disabilities was found in previous research to be an effective method to promote social networks and improve quality of life (Davidson et al. 1999; Mead et al. 2001). As demonstrated by Marcus (2005) friendships with others who also have a disability enhance a person’s sense of acceptance and belonging. It seems that peer support was highly valued by men in this current study. A range of views were reflected in the findings in relation to the importance of shared interests and values as well as the shared disability-experience. It was important to participants to have friends with a disability; however having the disability experience in common was not enough to base a friendship on; men must have hobbies and interests in common also. Current peer support groups focus on grouping disabilities together. The findings of this study show there is a need to have a more broad range of support services available to people with a disability, based more around their hobbies and interests rather than their diagnoses. A number of studies have documented how engaging in shared interests had positive effects on older men’s social and emotional health (Morgan et al. 2007; Ballinger et al. 2009; Ormsby et al. 2010; Cordier and Wilson 2014). This illustrates the power of taking part in meaningful occupations with like-minded peers. While it was important to the participants to be around others who had similar difficulties in order to feel comfortable it was also necessary to have interests in common with them. In keeping with the findings of various other studies on friendships, shared values between friends helps enhance self-identity and gives people a sense of belonging (Newton et al. 1994; Knox and Hickson 2011; Northcott and Hilari 2011).

**Implications for occupational therapy**

These findings have relevance for occupational therapists working with older men with disabilities. Supporting clients to create and sustain social networks is a fundamental responsibility for occupational therapists, as social participation is a key occupation associated with health and well-being (Holt-Lunstad et al. 2010). Occupational therapists acknowledge that engagement in leisure pursuits is an important part of a person’s roles and routines in everyday life and impacts on a person’s well-being (Pierce 2003; Kielhofner 2009). This study supports the view that assisting older men to remain engaged with their social networks and to remain involved with their communities is vital to protecting quality of life as they age (Fratiglioni et al. 2004). This study demonstrated that peer support may be more beneficial to older men if it were structured around shared interests and hobbies, as well as shared disability-related issues. Many peer support groups at present are formed on a
diagnoses basis. Occupational therapists could shift this focus from being disability-specific to occupation focused, which would allow for men’s interests to be at the core.

**Limitations**

It is acknowledged that there are limitations to this study. The interviews were not carried out by the author of this paper. However, they were conducted by experienced researchers as part of a bigger project; their knowledge and skill resulted in high quality interviews. While this researcher was not involved with the data collection, more time was devoted to reading fieldnotes, becoming familiar with the transcripts and a significant amount of time was dedicated to coding and analysing data. The contextualisation of the background of interviews was important in the analysis process and spending more time coding allowed the researcher to run several queries through the Atlas.ti software thus verifying the dependability of findings. All participants were able to communicate verbally and were relatively independent therefore the findings may not apply to more severely impaired or non-verbal men in this age category. The findings of this study may be interpreted with caution as it is a relatively small study completed by a novice researcher; the findings could be confirmed through further research.

**Recommendations for future study**

Due to the data for this study being extremely rich, many other areas within this cohort could be studied further. For example, environmental influences on experiences of stigma was a noteworthy observation within the dataset but was not under the remit of this current study as it was not an objective of this research. However, it would be worth investigating further to better understand how socio-economic backgrounds, environments and where a person resides can affect the experience of disability, stigma and supports available. It would also be interesting to complete a similar study on how women of this age group with disabilities approach friendship, in order to compare and contrast their experiences. Further research involving younger men could be compared with the strategies used by men in this study to help confirm whether the results apply to older men specifically.
Conclusion

This study outlined a number of strategies used by older men with a disability in Ireland to sustain friendships and create social participation opportunities within their communities. The main themes that emerged were ‘community involvement’, ‘shared interests’ and ‘peer relationships’. This study contributes to the limited knowledge of how older men with a disability in Ireland access friendships and social participation in their communities and emphasises the importance of meaningful occupation and peer support. It revealed that there appears to be a juxtaposition between maintaining social engagement with the wider community through shared roles occupations and on the other hand a need to develop and maintain relationships exclusively with those who also have a disability. It is clear from the findings that there is a need to have a balance of the two. Peer support may be more beneficial to older men if it were structured around shared interests and hobbies, as well as shared disability-related issues. Occupational therapists have a role to play in facilitating opportunities for men to engage in meaningful activities at a community level.

Key Findings:
- Older men with a disability in Ireland use effective strategies to create and sustain friendships in their communities.
- Occupational therapists need to effectively support men to maintain their social networks through promoting ‘community involvement’, ‘shared interests’ and ‘peer relationships’.

What this study has added:
- The findings provide awareness for occupational therapists of their role in promoting social engagement for older men with disabilities through occupation-focused peer groups.
References


National Disability Authority (2011) A National Survey of Public Attitudes to Disability in Ireland, Ireland: National Disability Authority


