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How do men with depression during the mid life transition, navigate stigma?

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Abstract:

Background: Depression is the second highest cause of disability worldwide. People who experience depression also experience stigma. Depression is a gendered diagnosis, and adds another layer of stigma for men who suffer it. The transition to middle adulthood is considered a time of crisis (Levinson 1977). This research will be part of the potential contribution of a larger project called ‘Navigating Stigma to Build Real Communities’ which will describe the experience of social inclusion in Ireland.

Objectives: This study highlights how men with depression, aged 35-50, navigate stigmatisation in their daily lives. This qualitative study explored the subjective experience of three men, living in Ireland, who self identified as suffering from depression.

Methods: Data was collected using a semi-structured interview and the subjective experience of these three interviewees was the source of raw data. These were audio recorded and later transcribed. Thematic analysis was carried out.

Results: Analysis yielded two overarching categories representing: strategies for navigating stigma and masculinity. Three subcategories emerged from the data highlighting how masculinity can be connected to productivity, control and vulnerability and four subcategories emerged in relation to how these men navigated stigma.

Conclusions: This research will contribute to the body of knowledge around the experience of depression for men and provide a rationale for the design of more gender specific interventions in practice. Occupational therapists can play a role in promoting accessible and non gender threatening interventions. The importance of considering the role of masculinity and vulnerability in men’s mental health programmes is highlighted.

Introduction

The World Health Organisation [WHO] (2012) recognises that mental health conditions can be disabling and according to the UN convention on the rights of people with disabilities (2006), this disabling mechanism is intrinsically linked with social barriers such as stigma. Negative beliefs and attitudes in the public arena about people with mental health conditions can trigger rejection, discrimination and reinforcement of stereotypes (Lai et al 2000, Schulze and Angermeyer 2003). Discrimination against people with disabilities is called ableism (Darling 2003, Stone 1995, Harpur 2012). People who experience stigma can suffer adverse effects which impact heavily on their relationships and social functioning, and internalisation of these societal perceptions is common (Link and Phalen 2001, Link et al 1997, Goffman 1963, SAMHSA 2004). Stigma can be a barrier to creating socially inclusive and sustainable communities for people with disabilities (Link and Phalen 2001, Green et al. 2005, DOHC 2009).

Stigma and its associated challenges was identified as the most pivotal challenge for people who live with a mental illness (WHO 2012, WPA 2011, NESF 2007) and overcoming these challenges is an issue of great importance to current and future mental health policy (WHO 2001, WHO 2005, DoHC 2006). Stigma is understood as labelling, stereotyping, separation, status loss, and/or discrimination (Link and Phalen 2001). This research poses the question: How do men with depression during the mid life transition, navigate stigma? The research aims include, identifying strategies used to manage stigma and to understand the qualitative experiences of double stigmatisation in the lives of men living with depression. This study will contribute to a larger project that will describe the experience of social inclusion in Ireland called 'Navigating Stigma to Build Real Communities'.

Table 1. This table outlines the details of the literature search.

Literature Search	
Search period	January to April 2012, September-April 2013
Keywords	depression, mental health, stigma, gender, midlife and men, vulnerability, masculinity
Databases	Medline, Science Direct, PsycARTICLES, PsycINFO, Pubmed, Cinahl, Biomedical Reference collection, Google Scholar, Academic search complete, the Allied and complimentary medicine database, Communication and mass media complete, General science, Omnifile, Social Sciences and Web of Science as well as grey literature

Literature Review

Depression is predicted to be the second highest cause of disability worldwide by 2020 (WHO 2012). It can impact heavily on occupational functioning, social participation, building and sustaining relationships and livelihood and can have a broader economic impact on families and communities (Lloyd et al. 2005, Lai et al. 2000, IPH 2006, WHO 2001). High levels of perceived social rejection are associated with depression, lower well-being, disability and chronic illness, and these can also increase the risk of mental health problems (ESRI 2010). People with depression experience social vulnerability because they are subjected to stigma, restrictions in the exercising political and civil rights and limitations to participation (Chan 2012). Vulnerability encompasses the experience of uncertainty, taking risks and being emotionally exposed (Brown 2012). Depression disrupts daily life for the men and women who experience it but the expression of symptoms can vary between the sexes and can be described as gender specific (Branney and White 2008, Zartaloudi 2011, Cochran and Rabinowitz 2003, Piccinelli and Wilkinson 2000). For example alcohol and substance abuse are often the primary diagnosis for men with depression, yet these are not included in its diagnostic criteria (Branney and White 2008, WHO 2010, Link et al. 1997, Piccinelli and Wilkinson 2000). It is thought that men may not express stress and anger like women, but

rely on means such as distraction, denial, disengagement, alcohol or drug use, compulsive behaviour and suicide (White 2002, Zartaloudi 2011, Peate 2010). Men are also more likely to be homeless and less likely to have sufficient support systems than women (Forchuk et al 2009). Internalisation of social stigma is most common among men (Vogel et al. 2007).

Women are reported as more likely to suffer from depression than men but it is documented that men report and seek treatment far less than women (Forchuk 2009, White 2002, Zartaloudi 2011, Piccinelli and Wilkinson 2000). Research suggests that depression in women is over-represented and that rates of suicide and substance abuse possibly reflect an underrepresentation of depression in men (White 2002, Forchuk et al 2009, Cochran and Rabinowitz 2000, Zartaloudi 2011, Nazroo et al. 1998). Gender is a social determinate of health and the feminisation of diagnoses can be challenging to masculinity (White 2002, Zartaloudi 2011). Historically, depression is considered a feminine condition (Piccinelli and Wilkinson 2000) and this adds another layer of stigma for men who suffer from it. Robertson (2004) points out that the experience of men as gendered beings is rarely visible in research and has led to an underrepresentation of the experiences of men with disabilities.

Levinson's concept of adult development presents the era of transition to middle adulthood as a period of crisis (aged 35-45). During this era men typically take on more responsibility and authority, are under more pressure and have more burdens than when they were younger (Levinson 1986). This period is one of re-evaluation and questioning where men review their accomplishments and plans in life but may experience intense dissatisfaction in doing so (Levinson 1977, 1986). It is proposed that men's feelings at this time are repressed and as a result, clinical depression is a typical hallmark of this stage of life (Levinson 1978, Kittrell 1998). This relationship between stressful life events and depression is supported in the literature for this age group (Piccinelli and Wilkinson 2000, IPH 2011).

The social and gender roles expected of men during the middle adulthood (aged 35-65) tend to leave them vulnerable to daily stress (Schaub and Williams 2007, Allmeida and Horn 2004). Gerschick (2000) talks about how successful gender performance can be validated by status and acceptance while failure in performance invites rejection through embarrassment and humiliation. Pressure to conform to dominant masculine norms are related to poor attitudes towards help seeking in men and research in this regard helps to understand men's difficulties in responding to disability (Mahilik et al. 2003, Vogel et al. 2011, Connell 2005). Although the expression of depression may be different for men than women (Branney and

White 2008, Zartaloudi 2011), social support and relationships may impact positively on symptoms of depression for either gender (Piccinelli and Wilkinson 2000). Men with depression may experience a double layer of stigma because depression is a gendered diagnosis which is already stigmatised because it is a mental health condition.

This research will contribute to the body of research describing the experiences of people with disabilities in Ireland. It will inform how clinicians approach working with a client group that may be affected by stigmatisation or double stigmatisation. This research also highlights the need for specific interventions around this particular client group, who may require gender specific interventions because they have a gendered diagnosis. It is hope that clinicians will be encouraged to become more mindful of the sensitive nature of gender and disability in relation to managing diagnoses, avoiding social isolation and the impact on health and well-being.

Methods:

This qualitative study fits well with critical disability theory, under the auspices of critical theory, allowing this paper to take the position that stigma already exists in society and that certain communities in Ireland and all over the world are stigmatised (Guba and Lincoln 2005, Goodley and Moore 2000, UN 2006). A qualitative design allows for explorations of feelings, opinions, expressions of emotion and the subjective experiences of participants (Yin 2011, Coffee and Atkinson 1996). The research question demands inquiry into the individual accounts and experiences, which justifies this design.

Procedure:

Qualitative research methods were employed during this project (Yin 2011). The study was exploratory, using in-depth, semi-structured interviews to investigate the experiences of stigma. The template for the interview guide, provided by the supervisor, was discussed and reworked by the research team and advice was sought from an impartial third party. The interview questions were designed to access information about different parts of daily life and experiences of stigma. One-to-one interviews were used so that information could be clarified at the point of contact. This increased the credibility of the information obtained by ensuring that the interview accurately reflected the ideas of the participants. In addition, the researcher

kept a field journal in order to document and account for her reflections around the data collection and analysis process (Emerson et al 1995).

Data Analysis:

Interviews were transcribed, cleaned of any identifying information and a code list was developed manually and with the help of NVivo 9 (data analysis software). Discussions with the supervisor contributed to forming a code list, a mind map outlining preliminary analysis and a summary of analysis. Further discussions with the supervisor around understanding the emerging findings within the broader context of the literature, gave rise to deeper analysis and dependability of research. Thematic analysis guided by Braun and Clarke (2006) and Emerson et al. (1995), was used to move from coding transcripts to category identification.

Participants:

Participants were recruited over a period of 12 weeks through gate-keepers, identified through non-HSE mental health services. An information letter and recruitment poster was supplied to gatekeepers made this information accessible to service users. Any interested parties contacted the researcher via email. Five students from the research team pooled their recruitment efforts and interviewing power. From the bank of interviews collected, three fell within the remit of this study: male, between 35 and 65, diagnosis of depression as a primary or co-morbid condition. The participants were aged 36, 45, 46 respectively. All participants self identified as having depression and one had a lower limb amputation.

Ethics:

People with mental health illnesses are considered to be a vulnerable group in society (WHO 2012) thus it was crucial to attend to ethical issues pertinent to this population. Discussion of informed consent focused on voluntary participation, confidentiality and disclosure. Consent forms were completed with each participant who was assured that consent could be revoked at any stage during the data collection or analysis part of the study. Information concerning the interview and project was supplied to potential participants in an accessible manner. This was forwarded via email, allowing time to read the material in their chosen environment or to discuss with a third party. Participants could access further clarification and reassurance from the researcher or supervisor at any time.

A risk assessment was completed by the research team. Plans were put in place to ensure the safety of researcher and participant. The participant was notified that he was free to contact the researcher about any amendments to their interview. In order to maintain confidentiality, all identifying information was cleaned from the transcripts and a pseudonym was assigned to the participant. Ethics approval was obtained by the research supervisor, from the Marie Curie Ethics Review Board and from the Faculty of Education and health sciences research ethics committee at the University of Limerick.

Results

In order to address the research question and aims, codes were identified and grouped into 8 subcategories. Commonalities were identified between these, yielding two categories, namely, strategies for navigating stigma and masculinity. Each category will be explored further under its subcategory headings.

Table 2: This table shows the cluster of codes in each subcategory and their strength

Subcategories	Codes	Participant 1	Participant 2	Participant 3	Total
Challenging stigma	Directly challenging those who stigmatise	9	34	7	50
	Challenging stigma in society				
	Being super 'able'				
	Disrupting ableism				
	Seeking opportunities for achievement/productivity/purpose				
	Participating in productivity				
Awareness of stigma	Acknowledgement of stigma	22	10	9	41
	Recognising stigma				
	Avoidance of stigma				
	Anticipating stigma				
	Protecting oneself from stigma				
Belonging	Withdrawing from stigma				
	Sense of belonging	8	15	1	24
	Peer mentorship				
	Othering				
	Disability pride				
Participating in group activities					

Passing as normal	Fulfilling societal expectation Fulfilling gender role norms Normalising depression Passing as normal	8	10	4	22
Controlling self disclosure	Controlling to whom you self-disclosure Not controlling self-disclosure Controlling timing of disclosure Controlling quantity/quality of details surrounding self-disclosure	7	2	6	15
Productivity	Self image as a productive being Importance of being active Achieving Providing	8	7	5	20
Control	Regaining Control Loss of control Regaining roles	3	14	2	19
Vulnerability	Difficulty with being vulnerable Access to vulnerability Vulnerability as a strength Helping others more vulnerable	11	29	1	41

Category 1: Strategies for navigating stigma

Challenging stigma

This strategy was the strongest subcategory. By overtly challenging societal views of disability, participants could also challenge discrimination against them. This method of managing stigma was used by all participants at some point during their illness experience and represented a powerful force against stigma.

There's 60 teams, there's over 4000 people watch this over 2 days. We will turn up on the day and we'll have our tracksuits on and no one will know, and we got a bag of crutches behind us...and then people will just take off their trousers and take off their legs and leave them by the field.....we're not disabled, we're abled.

In this example, the participant showed how disrupting ableism (Harpur 2012) could be a significant means of challenging stigma. He stated that his fundamental goal was to play soccer but that it was necessary to highlight the barrier to social exclusion they had to overcome in order to achieve that goal. Although this participant chose a very public stage on

which to pose this challenge, other participants found equally creative and unexpected ways to challenge stigma that were more subtle and thought provoking:

I got back to work and this fella said “you do know they’re calling you the devil?” So I turned around and I said well I have a fierce problem with that says I...if I’m the devil then where’s our Lord? There must be two of us the devil and our Lord. Yer man got an awful fright, he wasn’t expecting it

This challenging of stigma appears to stem from a heightened sensitivity to discrimination in society by people with disabilities (Goffman 2009) where seemingly invisible prejudice is revealed and exposed by those who challenge it. Disrupting ableism is recognised in the literature as one of these strategies (Goodley 2012).

Awareness of stigma

Within this research awareness of stigma is the umbrella term used to understand a combination of strategies including acceptance, acknowledgment, recognition, avoidance, withdrawal from, and anticipation of stigma (table 2). All participants described an innate awareness of stigma. Participants did not always challenge stigma; sometimes a heightened awareness of stigma and an understanding of how stigma can manifest in society, was enough to manage it.

And people don’t help either...they kinda think you’re mad. And there’s a stigma about it. And I don’t think that’s right...But that’s the way we were all brought up... And the old generation, that was bred into them because they said, look, he’s a bit odd. In other words he was mad ya know. They only suffered with depression...they only needed someone to talk to.

Although, awareness of stigma is the second most frequently referenced strategy in the data, it is important to say that the strategy did not always manifest as a heightened form of awareness. Sometimes it is described in the data so casually that it was interpreted by the researcher as an inherent sensitivity to societal attitudes towards disability, and a defaulted position of defence against a somewhat normalised state of acceptance of societal prejudice, stemming from an internalised understanding of how society views disability.

Belonging

This subcategory is made up of references to strategies such as disability pride, peer mentoring, distancing from other disabilities and participating in group activities (table 2).

While some participants wore their disability like a badge of honour, others were empowered by the energy of a group entity and as a result did not interpret stigma in the same way with the group than if they were alone. This is an example of a group of athletes with prosthetic limbs, going through airport security:

we were coming through customs and we all started to get a fit of laughter, we were...like village of the damned, kept taking off all these bits and pieces beep, beep...broken people coming through... But then the lads learned to laugh at themselves and see the funny side, whereas before they'd have been embarrassed, because they did (it) as a group.

Two of the participants within this data set were presented with opportunities for 'belonging' through participation in team sporting occupations. Being involved in a shared activity reflected an empowerment of the person and increased resilience to stigma through team solidarity and combined sense of disability pride.

Passing as 'normal'

This subcategory comprises some interesting ideas that point towards the layers of stigma that a man with depression, at this stage of life, may encounter and how they might manage it. Passing as 'normal', in this data, references the normalisation of depression, conforming to societal expectations and fulfilling gender role norms (table 2). This is an example of how a participant, on the cusp of middle adulthood, experienced the disabling effect of societal pressures and the inadequacy imposed by such social norms around accomplishment, level of productivity, role of provider and status:

I realise there are things I want, and I would like a job. I found...when you go out...with people and one says, oh I'm busy at work and this is an interesting job...suddenly you feel you can't get involved in them conversations...what are you gonna say, oh I watched Jeremy Kyle today...you don't fit in...and that's the isolation I felt cos people would be talkin about work...their new job...going on holiday. Whereas now I can say oh yeah I got this project going, and I have more interest in life

One could say that a man of this age experiences a double layer of stigma due to having a disability and a feminised diagnosis. But he also encounters another layer of discrimination as

a man who experiences isolation during this life stage, because he does not fulfil the social expectations for this age group and gender.

Category 2: Masculinity

Productivity as a characteristic of masculinity

The idea of masculinity and the experience of depression being at odds, surfaces in the data. Depression itself is not perceived as being ‘manly’ by the participants, which references the existence of a double layer of stigma found in the literature. The data shows that these men see themselves as productive, independent and purposeful beings. These qualities match some of the characteristics of gender role norms for men.

I was always busy...I worked 50-60 hours a week and the only way I knew to unwind was sittin in a pub...relaxing and having a few drinks cos you couldn't switch off. So that was my life

Being productive, accomplished and fulfilling career dreams sits well with the expectations for a man at this life stage, according to Levinson (1977) and Vogel et al. (2011) describes dominant masculine characteristics as being self-reliant and independent. The participants in this research describe their illness experience akin to, negotiating the terms of their disability with their ability to maintain their male roles and sense of masculinity.

Control

Control is understood within this study through references to being in control and regaining control (table 2), which fit well with dominant masculine characteristics (Vogel et al. 2011). But for these participants, also experienced loss of control and stability, which challenges both gender norm characteristics and life stage expectations for this age group (Levinson 1977). This example demonstrates how a participant struggled to maintain control:

they told me I would have to go on disability and I was afraid then that disability would cut me off [if I worked]...and I ended up going back into hospital with depression coz my bills were mounting up, my job was on the line and my house was on the line...everything was on the line...I tried everything

There was a surprising polarity surrounding the concept of control for these participants and a balancing act ensued throughout their illness experiences between control and vulnerability. Interestingly, this polarity was referenced by all participants but expressed very differently.

Vulnerability

Vulnerability does not fit as well with typical masculine characteristics. This subcategory emerges from codes such as, fear of weakness, avoidance of help-seeking, and difficulty being perceived as weak (Table 2). But participants also referenced vulnerability as a strength, ease of access to vulnerability, vulnerability as a turning point in the illness experience and respect for vulnerable traits in others. Overall, a negative perception of vulnerability was depicted as unhelpful during their illness experience. For another participant, vulnerability was embraced and expressed comfortably:

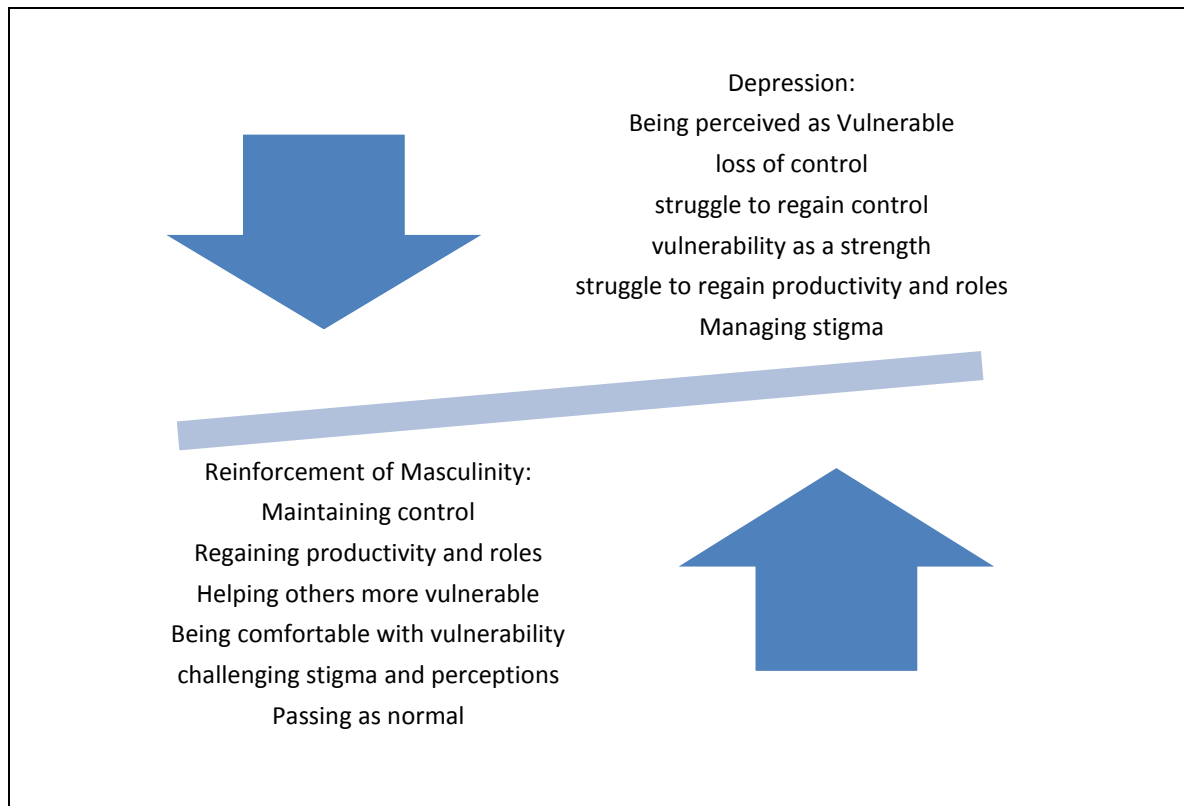
They'd know I suffer with it...but then again, I think one or two of them probably do too and they don't talk about it, because it's not a manly thing to say that you suffer depression or you cry or whatever. It's not a man thing is it, it's not macho. I mean, we're only human at the end of the day

This participant demonstrated his awareness of stigma towards men who experience depression. He shows sensitivity towards the origins of this discrimination and accepts its existence. Yet by embracing this knowledge, he minimises the internalising effect of stigma.

Discussion:

This study illustrates some of the strategies used to navigate stigma by men with depression during the era of transition to mid-life. It also sheds some light on the experience of double stigmatisation in the lives of this client group. To further understand these ideas, the results will be explored in connection within the broader context of the literature.

Fig. 1 The visual outlines the complex polarity between the experience of depression and masculinity



This research has highlighted a tension between depression and masculinity in relation to a problematic relationship with vulnerability, an expectation of conformity to social, gender and life stage norms, and an interconnected matrix of issues around stigma. Social expectations and inequitable gender role norms influence how men interact with others, express themselves and engage with health services (WHO 2007). Dominant masculine role norms are defined as stoic, controlled and self sufficient (Mahalik et al. 2003). Loss of control of emotion and inability to be self reliant can be a threat to masculinity (Schaub and Williams 2007). These sociological papers echo this polarity between vulnerability and masculinity. While gender role norms do not provide an accurate or a complete description of any individual, they represent a social kaleidoscope through which we perceive gender (Branney and White 2008). The experience of depression and strategies for coping with its associated stigma may be influenced by both gender role theory and self perception of depression (Branney and white 2008, Kelly et al. 2007).

'Vulnerable' is not a word which society associates with masculinity but yet it is necessary to facilitate human connectedness (Brown 2010). The research reflects the difficulty in resolving the tension between vulnerability experienced in depression and sense of masculinity. Self-reliance is one of the most basic expectations of masculinity that could result in a social undercurrent that pressurises men to keep up the pretence of self-reliance and avoid seeking help (Mahilik et al. 2003, Cochran and Rabinowitz 2000, Murray et al. 2008). Self perception of masculinity can be undermined by depression and social gender norms can reinforce this eroding process. Therefore the long term nature of many experiences of depression could seriously damage self esteem, self image and sense of masculinity (Addis 2008).

The illness experiences described in this research both challenge and affirm the notion of masculinity and are interwoven with references to vulnerability as a strength and a weakness. One of the participants expressed his duty to protect and care for the people who cared for him. Regaining control of his situation, life roles and levels of productivity, was followed by a strengthening of this sense of duty, protectiveness over others more vulnerable than him and a powerful reinforcement his roles and sense of self. This is characterised in this study as a journey of resolution between masculinity and vulnerability which involves a positive change in attitudes towards vulnerability and a reinforcement of masculine roles.

The idea of passing as 'normal' in times of disability or illness is a dominant discourse within sociology (Darling 2003). Goffman (2009 p.9) refers to it as the 'acquisition of fully normal status'. This idea is painted in a negative light in much of the literature because it often reinforces ableism (Harpur 2012, Goodley 2012). But 'passing' in terms of navigating stigma is interpreted here, as a survival strategy that allows engagement with daily life and occupations. These human rights can be easily compromised by the experience of stigma (UN 2006). Ridge and Ziebland (2012) refer to challenging stigma through re-casting depression as commonplace and integrating the depression experience into one's self concept. Of course strategies such as passing as 'normal' can be accessed by all people who experience stigmatisation (Darling 2003, Stone 1995). But the discrepancy between the societal norm for being a man and those characteristics of humanity that sit more comfortably with the female, such as vulnerability, create a gender conflict for men who experience depression. And this discrepancy may act as another barrier to dealing with the illness and contribute to male orientated behavioural patterns of depression such as alcohol dependence, drug taking and suicide (Branney and White 2008).

Awareness has often been spoken about in the literature, in relation to the experience of stigma e.g. heightened awareness and as Goffman (2009 p.14) describes, being 'on'. This research suggests that a global awareness of stigma can be an effective way to manage stigma. This study interprets the strategy of 'belonging' as a means of fostering a sense of resiliency to stigma by facilitating experiences of disability pride and solidarity and protection against isolation. But this strategy also facilitated access to the wider societal expectations for gender and life stage norms, regardless of disability, by providing opportunities for independence, productivity, fulfilment of roles and sense of achievement.

Challenging stigma or ableism can be understood as challenging a form of social oppression that restricts the activities of people with disabilities and undermines their emotional well being (Goodley 2012). The participants in this research challenged discrimination in a variety of ways: disrupting subtle or overt stigma, performing to a high level in their daily lives and achieving levels of productivity that would supersede the achievements of a typical able-bodied person. For some participants this strategy became part of their standard repertoire of coping with stigma. For others, acceptance of stigma (table 2) was frequently used and presented as a benign strategy in the findings. Different levels of acceptance was expressed e.g. indifference, indignation and defeatist. Acceptance appeared to come from a realisation that stigma could not always be easily disrupted or that the broader picture of societal stigma was far too complex for any one person to affect change. This relatively small finding is interesting as it suggests that for these participants, some forms of stigma were acknowledged as being so engrained in normal social practices that the presence of stigma was accepted as unrelenting.

Accepting stigma, passing as 'normal' and belonging, are presented in this research as viable strategies for navigating stigma. Managing symptoms and manifestations of their diagnosis in this way, allows people with depression to navigate the normal world, and avoid stigma, in order to facilitate participation and engagement in day to day life. Yet these strategies seem to be less disruptive to stigma than strategies such as challenging stigma and disrupting ableism.

Relevance to Practice:

This research will contribute to the body of knowledge around the experience of depression for men and provide a rationale for the design of more gender specific interventions in practice. Therapeutic programmes such as Men's Sheds, a movement towards building real

connections and peer support for men's mental health, could be a more relevant and gender specific approach to use in practise, with this client group (Vogel 2011, Morgan et al. 2007). Breaking down barriers to social inclusion should be a focus for clinicians. OT's have a unique role in redefining perceptions of what 'help seeking' might look like. As the participants have shown in this research, engaging in normal day to day roles and activities was central to regaining control in life. Healing through doing could be more attractive to men with depression rather than talk therapy and because OT's specialise in occupation based therapy, they may be best placed to promote accessible and non gender threatening interventions. The research points to the importance of considering the role of masculinity and vulnerability in mental health services, and how these factors may affect self perception. Kennedy (2001) says that a better therapeutic relationships can be forged if greater awareness is fostered by clinicians around the complaints and beliefs of men with mental illness.

Area for further research:

Grove (1999) says that there is a high priority attached to remaining or returning to work expressed by people with mental health challenges. From an OT perspective, productivity, purposefulness and motivation are guiding factors in development of interventions. This study highlights that productivity and sense of purpose can be an important force of motivation in the lives of men. Furthermore the relevance of the use of athleticism to counter the effects of stigma and the therapeutic value of physical activity for this client group were interesting ideas which surfaced within this data set. Two weaker strategies for navigating stigma were found during the analysis process but were not discussed within the remit of this paper: controlling self disclosure and disability education. Further data collection would yield more information regarding these strategies. The above areas warrant further investigation.

Limitations:

This study is limited by the inclusion of only 3 participants. Interestingly the participants made some common themes and subthemes discernible which suggest that some experiences might have wider representation. Due to the limited timeline for this project, the level of thematic analysis was more semantic than latent. For this reason more time would be required to achieve a fully theorised analysis and thematic saturation (Braun and Clarke 2006)

Conclusion:

The experience of men as gendered beings is rarely visible in research and has led to an underrepresentation of the experiences of men with disabilities (Robertson 2004). This study illustrates some of the strategies used to navigate stigma by men with depression during the era of transition to mid-life. It also sheds some light on the experience of double stigmatisation in the lives of these men. Social gender norms and life stage expectations may produce a third layer of stigma for this client group. Therefore, gender role theory and life stage theory may play a part in understanding this cohort. Strategies for navigating stigma were identified through thematic analysis and situated in the broader context of the literature. Masculinity is portrayed here, as being at odds with the experience of depression. Vulnerability, which is associated with depression and not with masculinity, is problematic for the men with depression. Vulnerability is a part of whole hearted living, and the perception that vulnerability is a weakness is dangerous and should in fact be considered a measure of courage (Brown 2012). This research shows that fighting against vulnerability was mostly unhelpful in the illness experience. Vulnerability can be challenging to masculinity but this study showed that resolving issues with vulnerability in relation to disability and masculinity can also be empowering. Supporting men with depression to build relationships and stay connected to people may promote better health outcomes (Forchuk et al. 2009). This study highlights the need for more gender specific interventions for men and the role of OT in redefining perceptions of help seeking, interventions and vulnerability.

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Appendix A: Initial Email Contact

This is the email script (and phone script) for point of first contact between Nancy Salmon, or a research student involved in this project, and potential participants.

Dear [insert name of participant],

Thank you for contacting me about the Building Real Communities project. The interviews will happen in summer 2012. We can have the interview in a place that you choose and feel comfortable in. We can make sure that the time we pick for the interview that suits you. The Interview will take about one hour.

This study will look at how people with disabilities in Ireland create lasting relationships in real communities. Nancy Salmon, a lecturer at the University of Limerick, is doing this study along with a group of research students. Over the next four years we will do interviews with many people in Ireland, creating a large collection of personal stories describing living with a disability, health condition or mental illness. Each student researcher will do up to 10 interviews. All together we will bring together the stories of over 150 Irish people with disabilities.

Being part of this study is voluntary and you can stop being part of the study at any time. If you choose not to stay in the study, it will not affect your access to services.

If you are interested in finding out more details about this study I can send you the research information letter by post or email. This letter explains in detail what the study is about and how you can take part. If you are interested in finding out more about the study, please let me know and I'll email it to you. Or you can let me know your postal address and I can send out the information sheet.

If you have any questions about the study please contact me.

Thank you for your interest in the study and I look forward to hearing from you,

Nicola Young 0804592@studentmail.ul.ie

0804592

Appendix B: Recruitment Poster



RESEARCH STUDY

Building Real Communities

In Partnership with
[insert name of
organization here]

For information
please contact
[insert name of
research student
here]

or

Nancy Salmon

Department of
Occupational Therapy
University of Limerick

(61) 234275

nancy.salmon@ul.ie

If you have [insert name of
disability or diagnosis here]
and are over 18 years of
age....

We want to hear about how
you build relationships at
home, at [school or work] and
in your community.



Appendix C: Information Letter



Building Real Communities

Many people with disabilities talk about being treated differently. You are asked to take part in a project to look at the stories of men between 40-65yrs who have depression, and how they build real communities with people who matter. This project will be done by a student researcher, Nicola Young, as part of her study in Occupational Therapy at the University of Limerick.

Areas we would like to know more about include

- 1) **Your time:** How you spend time during the day at home, at school/work, and in the community.
- 2) **Your friends and family:** Who you enjoy spending your time with and what makes those relationships last.
- 3) **When things go badly:** Times when you were treated unfairly because of having a disability or medical diagnosis.
- 4) **When you are treated well:** What makes life go well at home, at school or work, and in your community.

You will be asked to talk to Nicola Young for about one hour in a place where you feel at ease. For example, this could be a social club, a sports event, a library, your home or a quiet park. Nicola is a student occupational therapist. Your story will be recorded and you can have a copy of the interview if you like. You will be sent a short summary of the interview. All of the things you tell us will be kept private. Your name and details will not be in anything that is written about this research. There is no reward for taking part in the study.

If you would like to be part of this research, you must be over eighteen years of age. You must be willing to talk about times when you feel that you were treated differently because of having depression. Taking part in this project is completely up to you.

Please contact Nicola Young by email if you have any questions about this project at 0804592@studnetmail.ul.ie

You can also contact Dr. Nancy Salmon, Nicola's research supervisor by email at nancy.salmon@ul.ie or by phone at (061) 234275.

**If you have any concerns about this study please contact: Chairman
Education and Health Sciences Research Ethics Committee**

University of Limerick

Appendix D: Navigating Stigma Interview Guide

Part 1: Consent Interview

Review information letter and consent form with potential participant. If person agrees to be interviewed, then complete the following questions at the end of the consent interview.

Introduction

Thanks for agreeing to talk to me today about how you have made strong relationships at home, at school/work, and in the community. We will talk about how you spend your time and who you like to spend time with. Remember that you don't have to answer any questions you don't want to and that we can stop talking whenever you like. Are you ready to get started?

Day profile

- 1) I'd like to see how you spend your time during the day and on the weekends. So let's start with what a week day looks like for you [Fill out daily planner].
- 2) Does the weekend look different? [If yes, then fill out those parts of the daily planner]

People you like to spend time with

We all have many different kinds of people in our lives. Some people we share everything with, others are people we do things with. I'd like you to fill out this picture by putting the names of people you are closest to in the middle circle, people who you know and like in the middle circle, and people you only know a little bit in the biggest dark blue circle. The names of people you don't like but spend time with can be put outside the circles. [return to this diagram as a touchstone for rest of interview]

Tell me about who you've included in this diagram. [probe for the degree of intimacy in the relationships]

Now I'd like to talk to you about things you like to do.

Things you like to do

- 1) What do you like to do in your free time? [Use daily planner as a reference for this question]
- 2) Who do you enjoy spending time with? [Jot down names down as a reference point]
- 3) What do you like to do with these people? How much time do you spend with this

person? [Refer to names mentioned by participant, establish if any of the friends who have been mentioned share same disability experience or diagnosis]

- 4) Are you able to do all the things you enjoy with your friends and family?
[If no: what gets in the way?]
[If yes: is there anyone else you know who don't seem to get out and do as much as much as they would like, what stops that person from being able to spend time with family and friends?]
- 5) Would you like to do any of these activities more often?
[If yes: what would those activities be, where, with whom, how often?]
- 6) Would you like to do any of these activities less often?

Part 2: Full interview

Introduction

Thanks for agreeing to meet with me today. As you know this study is about how people with disabilities made strong relationships at home, at school/work, and in the community. Last time we talked about how you spend your time and who you like to spend time with. Today I'm going to ask you about times and places where you feel more or less comfortable. I will also ask you about anything that makes it harder or easier to do what you want to do in the day. Remember that you don't have to answer any questions you don't want to and that we can stop talking whenever you like. Are you ready to get started?

Being out in the Community

Some places are great to spend time at, while other places can be less comfortable. Let's look back over your weekly diary to see where you spend your time.

- 1) How many of the things you like to do happen out in the community? [refer to the weekday diary for prompts]
- 2) Where do you feel most comfortable when you are out with friends or family?
- 3) What is about that place puts you at ease?
- 4) Is there anywhere you ever awkward when you are out?
- 5) What makes that place different to the places that do feel comfortable?
[Probe for more detail: people, environment, interactions, activity, location, accessibility etc]
- 6) Do you prefer to socialise at home or out in the community? Why?

Workplace or School [only complete this section if person is working, has worked in the past or is attending school]

1. Now I'd like to hear more about the time you spend at work [or in school if participant is a student]. Can you take me through a regular work day? [might be reflected in diary].
2. What are the main things you do at work?
3. Who are the people you enjoy working with?
4. Are there people you prefer not to work with?
5. Tell me a recent experience you had working with people you feel comfortable with at work.

6. Tell me about a recent experience where you felt awkward or uncomfortable at work. What did you do to deal with this situation?
7. Does having a disability [or diagnosis] make any parts of your job difficult? If so, please describe.
8. Do people in your workplace know you have a disability?
 - a. If so, how did you share this information with them? Why did you decide to tell them? Did you tell co-workers and/or supervisors? Did disclosing to them changed your working relationship in any way?
 - b. If not, why have you chosen not to tell people about your disability?
9. Do you think you get treated differently than your nondisabled peers at work?
 - a. If so, in what way(s)?
 - b. [Here could give examples of subtle and obvious forms of discrimination in the workplace/school from recent newspapers or legal cases in Ireland].
10. Do you get treated differently by those who know about your diagnosis?
11. What are some of the good things about people at work knowing about your diagnosis? What things are not good about people at working knowing?
12. Would you disclose your diagnosis again in the future to co-workers or supervisors? Why or why not?

Being treated differently

[Note: If the person has not used the word stigma, use whatever word they did use e.g. discrimination or feeling uncomfortable or treated differently because of disability or diagnosis].

- 1) [Present some key findings from stigma survey in Ireland 2007]
- 2) I have an interesting newspaper clipping here in which a person with a disability talks about her experiences of stigma while socializing and how she feels that this restricts how much she socialises. Is that something that you relate to?
- 3) Do you get treated differently about as often as other people with disabilities?
 - a. Can you tell me stories from other people you know who are treated differently because of their disabilities? Why?
- 4) Have you ever been in a situation when you are out with family or friends where you were treated differently than people who don't have [insert medical diagnosis or disability]?
 - a. If yes, tell me about that.
 - b. If no, do you know any stories from others who have had this experience?
- 5) Where do you get treated differently most often?
- 6) What do you do when you are in situations where don't feel comfortable or safe? What works best for you?
- 7) Are these strategies similar to those used by others you know who also have [insert name of medical diagnosis or disability here]? [e.g. ask specifically about friends who have disabilities if participant mentioned them earlier in the interview]
- 8) Do you feel that these experiences affect your ability to participate in social activities?

Wrap Up

I would like to take a few minutes to be sure I have some of your personal details recorded correctly. Remember, this information will stay private and nothing you have said will be linked back to you in anything that is written or talked about from this study.

Participant Demographics (to be completed at the end of the interview)

- 1) Female/Male
- 2) Age
- 3) City or rural dwelling
- 4) Marital Status
- 5) Nationality
- 6) Housing: House, apartment, institution
 - a. How long in current residence?
 - b. Part of a housing scheme? Supported by a voluntary body?
- 7) Do you live with others? If so, are they friends or relatives?
 - a. Were able to choose who you wanted to live with?
 - b. Do you have any paid or voluntary support provided by others to enable you to live in your current residence?
- 8) How long have you lived with your [disability, medical diagnosis, mental health condition]?
- 9) How far did you go in your education?
- 10) Current employment status; work history
 - a. Training
 - b. If on work placement, who is support provided by
 - c. Doing job of own choosing?

It's been great talking with you today. You have given me a great deal to think about. Is there anything we haven't talked about that you would like to add?

I will send you a short summary of our talk today. Do you want me to send that by email or post? I am also happy to call you to talk through what is in that summary. Would you like me to do that? If so, please give me the phone number you would like me to call.

Appendix E: Consent Form



Agreement Form

Project Title: Building Real Communities

Introduction

You are invited to be part of a research project about how people with disabilities in Ireland create lasting relationships in real communities. Nancy Salmon, a lecturer at the University of Limerick, is doing this study along with a group of research students. Over the next four years we will do interviews with many people in Ireland, creating a large pool of personal stories describing living with a disability, health condition or mental illness. Each student researcher will do up to 10 interviews. All together we will bring together the stories of over 150 Irish people with disabilities.

The study is described below. Being in the study might not help you, but we might learn things that will help others. Being part of this study is voluntary and you may stop being part of the study at any time. If you choose not to stay in the study, it will not affect your access to services. . You will be asked to spend about 1.5 hours in the study. This includes the time it takes to get ready to meet Nicola Young and the time you spend together. If you have any queries about the study you can ask Nicola or Nancy Salmon.

Contact Information:

Address: Nicola Young
0804592@studentmail.ul.ie

Supervisor: Dr. Nancy Salmon

Phone: (061) 234275

Email: nancy.salmon@ul.ie

Purpose of the Study

The purpose of this study is to learn how people with disabilities in Ireland create lasting relationships at home, at school or work, and in our communities. Detailed stories about these relationships will be created.

What will you be asked to do?

Ten people with disabilities will be part of this study. If you agree, you can tell your story about making and keeping strong relationships with family, friends, and people at school or work. If you agree then your talk with Nicola will be recorded and later typed out. You can decide if things you say can be used when Nicola, Nancy or Fiona tell other people about this study. No one will be told the words are from you.

Who can be in the study?

Men, between the ages of 40 and 65, who use English or Irish, and who identify as having depression are invited to be part of this study.

Who will be doing the research?

Nicola will be doing this study with the help of his supervisor, Dr. Nancy Salmon and Dr Fiona Kumari Campbell. These people are able to read a typed up copy of what you tell Nicola. Dr. Campbell lives and works in Australia at Griffith University. She will only see your story Nicola takes out your name and any details that would give away who you are.

Keeping your story private

You will be asked to pick a fake name that will be used instead of your real name in the study. A paper that has both your real name and your fake name will be kept in a locked drawer in Nancy's office at the university. Your real name will not be used in anything that is told to others about this research.

The recording of your talk with [insert name of research student] will be stored on Nancy's computer. They will be in a hidden file in the computer and will be password protected. All information from the study will be stored in a locked office at the University of Limerick for 7 years after the study ends. Nicola will keep everything you say private unless you talk about abuse by a partner. Nancy has to report this to the local Gardai.

Your Rights

You can say that you don't want to answer any question that is asked. You can stop talking with Nicola at any time. She will not be upset and will stop right away. You can listen to the tape of your interview or read the typed copy. Nicola can give you a copy of the summary she writes about your meetings. It will not affect Nicola's schoolwork if you decide you want to stop being in this study. You can ask her any questions you want to about the study or you can talk to Nancy.

Can anything bad happen if you are in the study?

Sometimes things come up when people talk that can make you feel upset. Talking about your relationships might feel uncomfortable. You don't have to talk about anything you don't want to. You can tell Nicola you want to stop at any time. If you stay upset after the interview, Nicola can help you find someone to talk with to help sort out your feelings.

Will you get anything good out of being in the study?

There is no pay for being in this study. The study will not help you, but it could give us ideas that will help other people with disabilities make and keep good relationships. This study gives you the chance to think about what makes your relationships work for you. This may help you feel good about the people in your life.

**If you have any concerns about this study please contact: Chairman
Education and Health Sciences Research Ethics Committee**

University of Limerick



Agreement Form

I have read/heard the letter about this study. I have read/heard the consent form. All my questions were answered and I agree to be part of this study. I know that I am free to stop being part of this study at any time. I can ask for copies of my interviews.

_____ I know what this study is about

_____ I know that I will not be named in any reports or talks about this study.

_____ I agree that my interview with [insert name of student researcher] can be recorded.

_____ I agree that [insert name of student researcher], Nancy and Fiona can include things I say in my interview when they tells other people about this study. I know that I can change my mind about this until [insert name of student researcher] has written up the first full draft of her final report about this study in November 2012.

_____ I agree that Fiona Kumari Campbell from Griffith University in Australia can read my interview.

_____ I agree that my interview can be part of the big pool of life stories of people with disabilities in Ireland once my name and details are taken out.

_____ I was given a copy of the letter and this signed consent form.

Your Signature (or Parent or Legal Guardian)

Date

Researcher's Signature

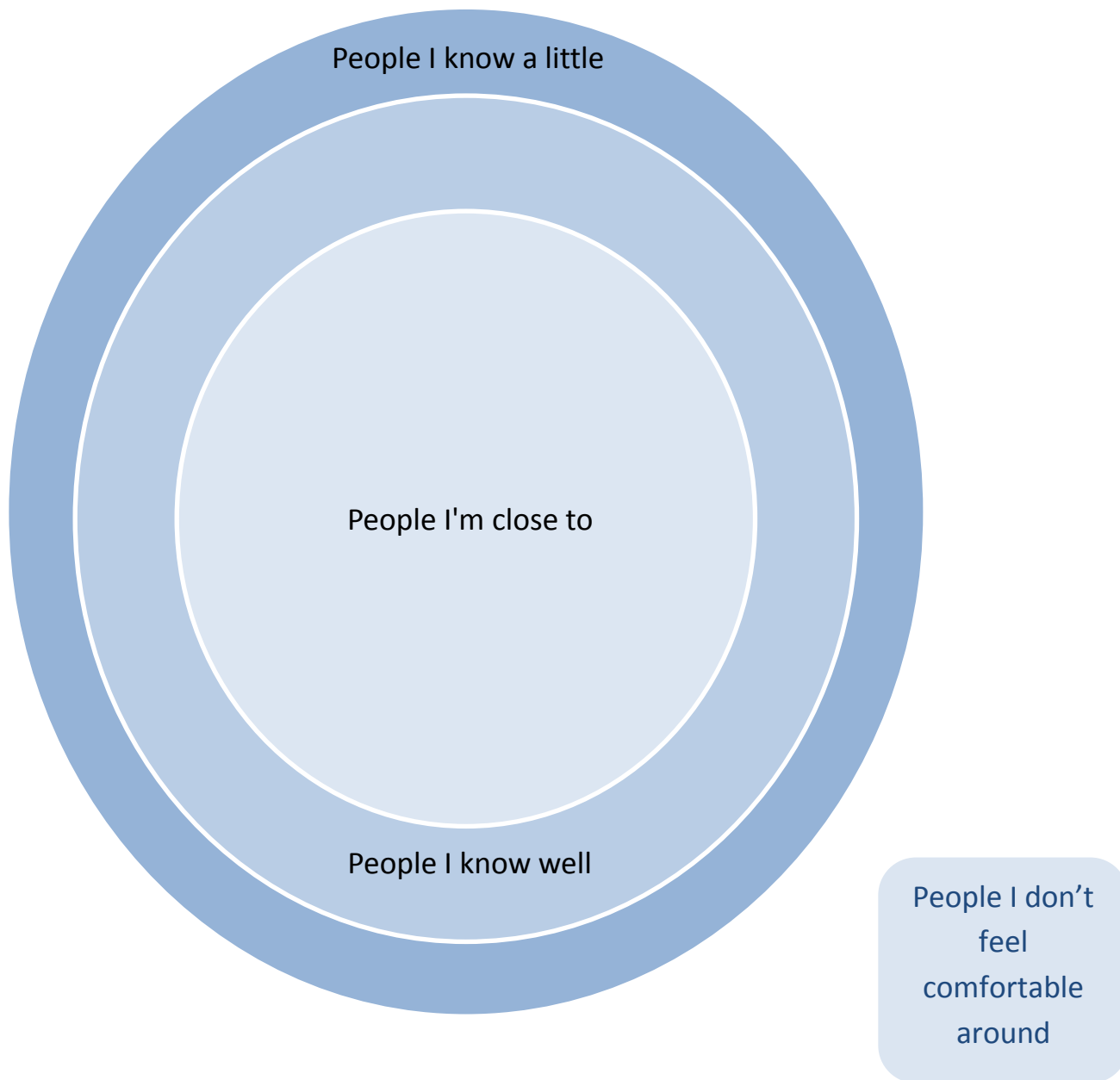
Date

Appendix F: Diary

Weekday Diary

Time	Activity	Alone	With Others
1am			
2am			
3am			
4am			
6am			
5am			
7am			
8am			
9am			
10am			
11am			
12noon			
1pm			
2pm			
3pm			
4pm			
5pm			
6pm			
7pm			
8pm			
9pm			
10pm			
11pm			
12 midnight			

Appendix G: People in My Life



Appendix H: Resources for Mental Health

First point of contact:

It is recommended that anyone experiencing distress related to mental health contact their GP to discuss the situation and for advice about what services and supports might be available.

Other services and supports include:

- 1. Aware:** This is a voluntary organization whose mission is “to create a society where people with depression and their families are understood and supported, are free from stigma and have access to a broad range of appropriate therapies to enable them to reach their full potential.”

Contact Information

Website: <http://www.aware.ie/>

Helpline: **1890 303 302**

Email: wecanhelp@aware.ie

- 2. Grow** is a voluntary mental health organization that helps people who are experiencing mental health problems.

Contact Information

Website: <http://www.grow.ie/>

Phone: 1890 474 474

Email: info@grow.ie

- 3. Limerick Mental Health Association:** This organization is connected to the national voluntary organization Mental Health Ireland. *“The aims are to promote positive mental health and support people who experience mental health difficulties”*

Contact Information

Website: <http://www.lkmentalhealth.ie/index.htm>

Phone: 061-446786

Email: info@LKmentalhealth.ie

- 4. Pieta House** offers counseling and support services to people experiencing a mental health crisis.

Contact Information

Website: <http://www.pieta.ie/Index.html>

Phone: 353 (01) 601 0000

Email: mary@pieta.ie

- 5. The Samaritans** “provides **confidential** non-judgemental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair”

Contact Information

Website: http://www.samaritans.org/talk_to_someone/find_my_local_branch/ireland.aspx

Phone: 1850 60 90 90

Email: jo@samaritans.org

Appendix I: Confidentiality Agreement



Before I access any information related to the Navigating Stigma to Build Real Communities Project, I understand that I am to keep anything I read or discuss with the principal investigator, co-investigator, or student researchers completely private. I will not discuss this information with anyone outside the project. I understand that I will not have access to the identities of any current or previous research participants. I will not make copies of any information in the qualitative database, nor will I take any information from the project away from UL campus without the explicit permission of the principal investigator. If I do not adhere to this agreement, I understand that my work on this project may be terminated immediately.

Research Assistant

Principal Investigator

