Title: Disclosure of epilepsy in young adult friendships

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Abstract

Discussions of disclosure within epilepsy academic literature focus primarily on the chosen targets and motivations for disclosing epilepsy. This current study contributes to the literature by describing the process of peer disclosure as reported by young adults with epilepsy. Semi-structured interviews were completed with eight young adults (18-25) with epilepsy recruited from a local epilepsy organisation.

Thematic analysis yielded four main themes connected to the process in disclosure of epilepsy: (1) *Assessing the disclosure recipient, (2) Managing the presentation of epilepsy, (3) Forging alliances* and *(4) Feeling more positive*. The research indicated that for these young adults the process of disclosure centres on their need to recruit support in the form of 'alliances' to help them manage the physical and psychological implications of living with epilepsy. This motivation was reflected in the participants' process of selecting a recipient; primarily choosing those they perceived to be reliable and trustworthy. It was also reflected in their disclosure messages; they were careful to construe epilepsy as non-invasive as possible so as to bolster their commitment to the role. The results indicated that as a result of engaging in this process participants felt safer, happier and more in control of their condition. However, it also revealed that disclosure was often impeded by concerns about gaining a stigmatised social identity. Considering the benefits of disclosing on the wellbeing of these participants, and the theoretical understanding occupational therapy has on the relationship between social engagement and wellness, it is argued that occupational therapists should play a more active role in promoting disclosure in this population. One practical way occupational therapists can do this is by setting up peer-mentoring programmes that promote the development of a positive collective identity within existing epilepsy organisations so that these youths feel less susceptible to feelings of stigma.

Literature Review

The decision to disclose or conceal sensitive personal information can be a pivotal moment in the social relationship of the individuals involved (Dunne and Quayle 2002). While disclosure can result in an increase in relational closeness and the creation of social support (Cohen and Wills 1985; Peterson *et al* 1996; Smith *et al* 2008), it can also lead to discrimination and a disintegration of the relationship between the parties (Hinshaw and Cicchetti 2000; Petronio 2000).

Disclosure of stigmatising health status

This decision becomes necessarily more complex when it involves disclosing a stigmatising, but concealable health condition. As employed here, stigma refers to a layering of social discrimination, prejudice and/ or discounting that an individual may experience as a result of possessing a characteristic that society views as undesirably different from the norm (Goffman 1963). Whereas some stigmatising health conditions such as Parkinson's are readily apparent to others by the presence of a tremor or adaptive aids, epilepsy and HIV depict no outward signs and thus can be regarded as concealable. Thus, disclosure is a unique psychosocial challenge faced by those with such concealable conditions. Moreover, disclosure can have a unique impact on their social relationships. Unlike those with visible impairments, where friendships are formed based on others awareness of their condition, those with concealable conditions often enter into friendships with others remaining unaware of their health status. In such cases, the decision to disclose often centres on the tensions between the fear of relational disruption (Kleck 1968), the desire not to be discredited as ill or disabled (Charmaz 1991) and the need to feel safe and maintain an honest relationship (Dunne and Quayle 2002).

   Epilepsy is a neurological condition that is particularly susceptible to stigma due to the unpredictable nature of seizures and the loss of bodily control that often accompanies them (Jacoby *et al* 2005). However, provided seizures are well-managed by medication, individuals can decide when and to whom they share their condition. This extensive power over potentially stigmatising information means that individuals with epilepsy must continually manage disclosure decisions in all their social relationships (Schneider and Conrad 1980).

   While the process of disclosing epilepsy in one's social relationships has not been explicitly described to date, the process of disclosing other stigmatising concealable

conditions such as HIV (Kimberely *et al* 1995) and hepatitis C (Dunne and Quayle 2002) in social relationships is evident in the literature.

Using maximum variation sampling, Kimberely *et al* (1995) recruited five women (aged 24–42), who were diagnosed as HIV positive, and analysed their disclosure experiences using grounded theory procedures. Kimberly *et al* (1995) describe these women's disclosure process in terms of a six-step model. For these participants, the first step in the process was adjusting to the condition. The participants felt ready to disclose once they had privately come to terms with the diagnosis. The following step in the process was a personal assessment of their disclosure skills. This involved assessing whether they could adequately relay the relevant information concerning their diagnosis. Next, participants evaluated the suitability of various disclosure targets. This involved taking account of their roles and the level of intimacy between them. Following this, participants further assessed these candidates for suitability based on their circumstances, i.e. age and health status. Consequently, candidates deemed to have complex social histories were not informed. Anticipating the recipients' response was the next stage in the process. Women choose only to inform those who they predicted would respond favourably to the information. The final step in the process was the women's own motivations for disclosing. This was of two types, support (emotional, childcare) and obligation (sense of duty to protect others).

Dunne and Quayle (2002) engaged in focus groups with 32 women with Hepatitis C to investigate the disclosure process. Interpretative phenomenological analysis (IPA) enabled the authors to identify five master themes; *seeking to control the disclosure process; fearing exposure; pressures for disclosure; pressures against disclosure*; and *consequences of disclosure*. '*Seeking to control the disclosure process'* encompassed the participants' desire to control who knew about their condition. '*Fearing exposure'* described the participants' fears about third-party exposure. '*Pressures for disclosure'* encapsulated the women's motivations for disclosure. These could be categorised into interpersonal reasons (protect others, maintain honesty), and intrapersonal reasons (emotional and practical support). The reasons against disclosure; namely privacy, stigma and protecting others from worry were encapsulated in '*pressures against disclosure'*. Lastly, '*consequences of disclosure'* denoted the interpersonal (rejection, support) and intrapersonal (hurt, withdrawal, acceptance) that resulted from their disclosures.

The literature on the process of disclosing a stigmatising but concealable health status indicates that, the decision to disclose centres on the tension between the fear of rejection and

the need for the recipients' support, with individuals choosing to disclose selectively rather than telling all.

Disclosure of Epilepsy

Research examining the stigma strategies in people with epilepsy offer some preliminary information on the process of disclosing epilepsy in social relationships, specifically the chosen targets and motivations for disclosing. The research indicates that disclosure is not a lone event, but rather is a continual process for some individuals while others opt to hide it to prevent being stigmatised (Kilinik and Campbell 2009; Kleck 1968; Rhodes *et al* 2008; Schneider and Conrad 1980). Further, consistent with research on other stigmatising conditions (Kimberely *et al* 1995), the distinction is often based on who needs to know, often for safety reasons. However, some participants discussed being very open about their condition (Kilinic and Campbell 2009).

There is clear support for the proposition that the anticipated social consequences of disclosure seem to be a significant influence on the decision to disclose epilepsy in social relationships. Perceived efficacy for self-disclosure to negate stigma, along with more positive reactions from the recipient were the most frequently cited constructs associated with disclosure (Kleck 1968; Santosh *et al* 2007; Schneider and Conrad 1980; Troster 1997; Scambler and Hopkins 1986). Another interpersonal function for disclosure was to "test" the strength of the social relationship (Troster 1997).Disclosure may be enacted to ensure that appropriate actions will be taken in the event of a seizure (Schneider and Conrad 1980; Troster 1997). Further, it indicated that disclosure had as therapeutic function for the individual in terms of greater self-acceptance and for catharsis (Schneider and Conrad 1980).

There is much need for more research into the disclosure of epilepsy as most of the research was done in the last decade, and so may not be relevant to today. Although, there might be commonalities in relation to many aspects of living with and managing a physical limitation, the social and political analysis of the day will most likely determine different systems and rules for governing the disclosure process.

Moreover, the process of disclosure may be different for individuals in diverse cohorts (Dindia 1997). Emerging adulthood (18-25) (Arnett 2000) represents is a particular interesting cohort to investigate the process of peer-disclosure as it is within this life-stage that peers play a significance role in their development by helping to facilitate the transition

to emotional autonomy (Ryan and Lynch 1989). Thus, one might infer that it is within this life-stage that disclosure has the greatest level of significance for the individual.

Research objective

This study explores the process of peer- disclosure in young adults with epilepsy (18-25). It builds on the previous qualitative research on epilepsy disclosure of Schneider and Conrad (1980), but will differ in that it aims to outline the process of epilepsy disclosure in its entirety, as achieved by authors investigating other stigmatising concealable conditions (Kimberley *et al* 1995; Dunne and Quayle 2002) rather than specifically addressing the functions and targets of disclosure. By providing knowledge of disclosure in an Irish context, this study will help occupational therapists working with this population to construct more effective and sensitive interventions.

Method

Qualitative research enables researchers to capture how people make sense of the world and how they interpret life experiences (Bryman 1988; Willig 2001). A qualitative research method was conceived to be most suitable method for addressing the aims of this study for two reasons. Firstly, it goes without saying that in order for a researcher to effectively delineate the disclosure process, he or she must try and understand the individual's interpretative processes (Bryman 1988; Denzin and Lincoln 1998). Thus, a qualitative approach was chosen as it permitted such an exploration. Secondly, it is commonly accepted in psychological literature that the experience of disclosure is embedded within a social domain, being a practice influenced by and reflective of the individual's relationships with the recipient (Murray and Chamberlain, 1999). Given this, the researcher believed that it would be fruitful to conduct her investigation in a qualitative manner, where she could get a sense of the relationship between the individuals involved (Murray and Chamberlain 1999).

Recruitment and participants

The criteria for inclusion were; a diagnosis of epilepsy for at least one year**;** an age between 18-25; and ability to read and understand English. Exclusion criteria were; the presence of rapidly progressing neurological or medical disorder; a history of psychiatric syndrome that

could limit participation; and a history of severe epileptic seizures in particular in response to phobic or pattern stimulation.

Two leaders of a local epilepsy organisation acted as gatekeepers in the recruitment process and mailed a recruitment letter and an information sheet on the nature of the study and its perceived benefits and risks, to all of its members who satisfied the above criteria on the researcher's behalf (See appendix A and B). Interested participants were directed to email the researcher for more information. The first ten participants who contacted the researcher were provided with an information letter; of these eight signed the consent form and engaged in research interviews (See Appendix C).

Procedures

Eight semi-structured interviews, lasting between 50 to 70 minutes were conducted in a location convenient for participants (See Appendix D for interview schedule). Seven interviews were audiotaped and transcribed. Field notes were recorded after each interview (Shaw and Gould 2001; Smith 2003). At the request of the participant one interview was not recorded; however, extensive notes were taken during the session.

Participants were asked to disclose their experience of living with epilepsy, how they manage disclosure-decisions in friendships, and their experience of disclosing in friendships. The researcher used emerging data to develop these questions in scope and usefulness over time. Specifically, the interview schedule was refined to more fruitfully explore the relationship between the discloser and the recipient, as well as the perceived outcomes on the relationships (See appendix).

Cleaned transcripts were emailed to the research supervisor for storage. All data will be deleted from the researcher's personal laptop as of May 2012 but stored in the research supervisor's office on a password protected computer per university policy.

Ethics

Ethical clearance approval for the research was granted by the faculty of Education and Health Sciences, Clinical Therapies Research Ethics Committee. Maintaining the confidentiality and anonymity of the participants were primary considerations in the ethical decision-making process. As the research topic is considered by many to be sensitive, the research took steps to ensure that the participants' informed consent was obtained freely. For example, the information sheet, written in plain English, describing the purpose and nature of

the research, the risks and benefits of participation and the right to refuse or withdraw consent at any time was mailed to all suitable candidates by the gatekeeper on the researchers behalf. Participants were reminded throughout that their participation was voluntary and that they had the right to withdraw at any stage. The participants also received a list of free phone numbers of third-party mental health organisations whom they were directed to contact if they became distressed by the topics discussed (See Appendix E).Steps were also taken to ensure the anonymity of the participants. Personally identifiable information was removed and only the age and the sex of the participant were recorded (Beauchamp and Childress 2001).

Data analysis

The data analysis used the method of thematic analysis as described by Coffey and Atkinson (1996) that is the process of coding, clustering codes to develop concepts or categories from the coding, and developing themes from these concepts or categories that help to clarify the phenomena under investigation (Coffey and Atkinson 1996). Throughout the analysis memos were written to develop ideas and to inform early in the analytical process. They helped identify which codes to treat as conceptual categories, and to separate emergent categories into their components (Wolcott 1994).

Trustworthiness

Credibility of the data was established by; adopting research method employed in previous studies; obtaining rich depictions of the disclosure process from the participants; frequent debriefing sessions with the project supervisor; seeking scrutiny of the data from the researcher supervisor; examining the finding of previous research to assess the degree to which the project's findings were congruent; and by member checking, where a summary of the research findings was emailed to the participants to elicit their feedback regarding how well the themes captured the essence of their disclosure experience (Patton 1990). Dependability was established by providing an in depth coverage of the research design and its implementation and by a reflective appraisal of the project. Confirmability was established by constructing an audit trail to allow any observer to trace the course of the research step-by-step via the decisions made and the procedures described. A concept map was also devised to

allow the observer to trace the manner in which the concepts in the research were devised (Guba 1981; Morrow 2005).

Reflexivity

This study addressed reflexivity by examining how the interviewer and the participants monitored each other's talk in interaction and how the coding process was executed (Finlay and Gough 2003). The researcher noticed that because of her background of working with young adults with epilepsy, the participants made assumptions that she would understand aspects of the condition without explanation. After noting, this trend, the structure of the interview was altered so that the participants were invited to define the terms they were using. The coding process was also analysed as a means to enhance the validity of the study. While, the researcher's connection to epilepsy was desirable on many levels it may have predisposed the researcher towards labelling the data to reflect that which she already knew. For example, she had a tendency to conceptualise all the concerns participants raised about their social image as a facet of felt stigma, without considering them first as a more general concern. To rectify this, the author discussed the analysis at regular intervals with her supervisor and constructed a concept map to reflect the themes as they emerged in the data.

Findings

The four main themes identified in the analysis were; *Assessing the disclosure recipient; Managing the presentation of epilepsy; Forging alliances*; and *Feeling more positive* (See Appendix F for associated categories). For all the participants the main consequence of having epilepsy was a decreased sense of ability in to author their own lives. All described

epilepsy as signifying a loss of personal control or agency. This diminished sense of control seemed to rouse the participants towards actively seeking ways to regain control. For the participants disclosure helped restore a sense of personal control in their lives by facilitating the recruitment of others as 'allies' in ther daily management of their epilepsy.

Assessing the disclosure recipient

The main obstacle facing the participants to disclose their condition to their peers was their perception of the social stigma. They described that they were cautious to disclose because in doing so they ran the risk of having their identities discredited. As Claire* notes,

' it is the kind of thing you need to keep to yourself in order not to create a reputation for yourself a bad one'

It also meant that the decision to disclose was a difficult one to make; arising only after weeks of agonising over the potential risks and benefits. Moreover, they all described disclosing on a need to know basis and only to those they trusted not to tell other. As Aileen* says:

"I would tell a couple of my close friends… trust that needs to be there before you tell people"

These participants choose only to disclose to those that they felt would not treat them any differently. Some participants described engaging in testing strategies to more accurately predict the recipient's response. For example, Martin* based his decision on whether the person had any close associates with a disability.

'be wary of the experience that they have in the area of disability'

Managing the presentation of epilepsy

Relatedly, most participants described putting themselves under pressure to present themselves and their epilepsy in a particular way. They seemed to do so out of a recognition that the manner by which they presented themselves and their epilepsy could work to either bolster or hamper their relationship with recipient and thus their commitment to their role as an ally. Most of the participants sought to increase their ally's commitment to the role by minimising the negative implications of epilepsy. Some were concerned that a candid

portrayal of the realities of their condition would not elicit support but would instead end the relationship. For example, Claire* noted,

"I could not imagine anyone wanting to be your good friend if you made out how bad it got or what it really meant'

This choice appeared to be both compelled, and enabled by the lack of public awareness concerning the condition. As John* summarises:

"people are a little bit dim in that area"

Others contributed to this depiction of a less intrusive condition, by emphasising their status as a well and healthy individual. Thus, these individuals sought in their disclosures to exaggerate their normalcy, productivity and competency. For example, Donna* noted that she told her friend,

'that it doesn't affect my thinking… that I able to do some things as good as her'

Other participants sought to increase the ally's commitment to offer support by making sure the disclosure were presented as voluntary choices. They felt that, presenting their disclosures as voluntary choices showed their allies that they trusted them, and in doing so would increase the relational closeness. As John* noted,

"it meant that I trusted her to tell her and that it would make us a closer."

These participants believed that an involuntary disclosure, such as by exposure, would not lead to increased regard but would result in accusations of dishonesty and secrecy, ultimately causing relational disintegration. As Deirdre* describes:

'that if I didn't tell her then she could think that I was capable of deceiving her … I didn't want things between us to end' .

Forging Alliances

Epilepsy is experienced as a source of oppression that leads people to feel a distinct lack of control over their lives. For the participants, disclosure was an active response to the condition that helps restore a sense of personal control or agency through facilitating the recruitment of peers to act as allies of their condition. This need for support was often precipitated by a move away from familial support, such as to go to college or work. Some participants felt disclosure channelled an obligation on the ally to help them with the day to day realities of the condition. As Claire* notes,

>*''I knew that she would take it as a thing for her concern is well'*

Furthermore, the participants felt this support would help them regain control over their lives by allowing them greater independence from the practical and psychological implications of the condition. As Martin* describes,

>*'If you are monitoring it and so is someone else than it cannot have half the effect'*

One aspect of their lives that it was felt these alliances enabled them more control was their future safety. All of the participants acknowledged that they counted on their chosen recipient to take charge and ensure their safety in the event of seizure. Participants typically gave the recipients educational information about seizures and instructions about what to do should a seizure occur. As Mary* notes,

>*"I always say please don't (call and ambulance).. make sure that my head is safe'*

Some participants relied on their ally to take mutual responsibility for the information shared. For the participants this meant that the allies were willing to help conceal their epileptic status from unknowing and naïve others who could use the information against them Participants described engaging in negotiated concealment strategies designed to prevent unwanted others from becoming aware of their epileptic status. As John* notes,

'when others start quizzing me about how come I don't have a driving license she takes the attention away ...it's a shared thing now whereas it was just me before trying to hide it all by myself'

 Having a close alliance meant that the participants had a non-judgemental forum to discuss the concerns they would have previously kept suppressed. Getting the chance to discuss these concerns benefitted participants. They described actively holding back on these suppressed worries escalating into fundamental preoccupations in their lives. Participants reported that these worries were becoming fixed ideas became emotional weights that they longed to be free from. As Martin* and John* recalls,

'I was starting to obsess about it....now I am not swamped down by the bad'

'I couldn't handle dealing with all the stress of my worries (.) they were taking me over'

Moreover, they described that having to continually address and readdress these concerns in isolation left them unable to fully focus adequate attention on other aspects of their live. The participants noted that having someone to discuss their concerns with was a process that served to banish these concerns from the forefront of their minds. Martin*, John*, Mary*and Eimear* described taking on board the advice of others as a means to minimise these concerns. As Eimear* notes

'if it was left up to me I would assume the worst. I needed a bit of common sense and like she would be the one to say that'

For others, merely being given the opportunity to air their emotions helped them to reduce them of their emotional intensity. As Martin* recalls,

'telling others is good way of helping you deal with the anger and hurt ...it makes the whole thing a lot more manageable'

Feeling more positive

Forging alliances through disclosure is tactical in that it subsequently allows the participants to minimise the impact epilepsy was having on their everyday lives. Having such support meant that they felt more control over their condition which made them feel happier, safer and more relaxed. As Mary* describes,

'I've got it under control.. things are lot happier and a lot safer as well'

Some expressed that having someone monitoring their epilepsy in a manner determined by them meant that they worried less about the unpredictability of seizure occurrences. Further, some participants described that having someone to discuss their condition-related concerns with helped them to obsess about them less, and thus allowed them to regain a sense of connectedness to their environment. As Claire* notes,

'''it became the only thing I could concentrate on… that means you are not really with it'

Discussion

This study explored the process of peer disclosure in a group of young adults with epilepsy, to better understand the convergence of systems involved disclosure process. All relevant theoretical approaches outlined in the literature review, specifically, the findings of Kimberley et al (1995), Dunne and Quayle (2002), Schneider and Conrad (1980) and Troster (1997), have been shown to be relevant and feature both within and across the themes and subthemes.

   The findings indicated that epilepsy is experienced as a threat to one's sense of agency and perceived control. Disclosure facilitated the recruitment of allies to help manage the day-day realities of epilepsy. These allies were relied upon to take charge in the event of a seizure, to provide emotional support and to act as gatekeeper of the information shared. Fundamental to this process was the selection of an appropriate ally. Similar, to the participants in Kimberely et al (1995), the participants engaged in a process of assessing the suitability of the potential ally. However, in differs in that these participants based their assessments based on perceived trustworthiness as well as relational closeness. To facilitate recruitment, most

participants described putting themselves under pressure to present their condition as benevolent as possible in their disclosure messages. This finding echoes that of Troster's (1997) where individuals' decision to disclose was partly motivated by a need to protect their social identities from unwanted connotations.However, in contrast to of Troster's (1997) study, the the participants in this study appeared to do so out of determination to maintain their friendship with the person to elicit their support. Consistent to findings of Kleck (1968) Rhodes *et al* (2008) and Schneider and Conrad 1980), stigma was identified as a significant barrier to disclosure.

Occupational adaptation is an intra-psychic process of adapting one's way of doing to deal with external stressors so as to preserve occupational participation (Schultz and Schkade 1992). Viewed through this prism, disclosure can be conceived as an adaptive strategy enacted to facilitate change in how people manage their condition so as to attain a more meaningful participation in life. These youth disclosed to their peers to build a support network to help them manage their conditions in new environments such as college and work, where their parental support network was no longer efficient. This move from a reliance on parents to a connection with peers is reflective of this life stage, with peers facilitating the transition to autonomy (Ryan and Lynch 1989). Forging alliances allowed these participants greater control over their mental health, safety and social identities in new and unfamiliar situations. This finding is similar to that reported in Ungar's (2001) study on marginalised youths, in which the youths described strategically forging supportive friendships to help them cope with the stress of being in the new terrain of an out-of-home placement.

While the creation of alliances is new to the literature on epilepsy disclosure, support for their roles can be found in the existing literature. Analogous to Troster (1997) and Schneider and Conrad (1980), the participants were motivated to disclose to ensure their future safety in the events of seizure. The experiences of these participants were closely aligned to Troster's (1997) study in this regard, as the participants' motivations for disclosing came solely from their own need to be assured of their future safety, rather than from a need to solve the problem that a seizure might represent for the recipient. The participants also disclosed to obtain help concealing their epilepsy from others. While this has not been explicitly stated as a function for disclosure to date, the recruitment of others to "covers" is a commonly cited practice among those with invisible illnesses (Greene and Serovich 1996).The participants disclosed about epilepsy so that they could be provided with a non-judgemental forum to discuss epilepsy-related concerns. Disclosing for emotional support is a well-established

motive for disclosing other invisible conditions such as Hepatises C (Dunne and Quayle 2002) and HIV Kimberely et al 1995).

The benefits of disclosing centred on the participants feeling happier, safer and engaged in life. To borrow from Wilcock (1998), disclosure resulted in a change of '*doing*' which in turn resulted in a change of '*being*' for these participants. Specifically, having others share their epilepsy-related concerns enabled the participants to minimize the emotional weight of their conditions. This conceptual finding is similar to that proposed by Schneider and Conrad (1980), indicating that disclosure was enacted to positively reframe epilepsy. However, it differs in that it was more to do with acceptance of how the condition impacted them rather than coming to incorporate it as a fundamental component of their identities.

Implications for occupational therapy

The main factor preventing young adults with epilepsy from disclosing their condition to their peers and thus gain access to a wider network of social support was their perception of the social stigma of the condition. Unable to build a supportive social network, many of the participants described engaging in maladaptive coping strategies such as social withdrawal and obsessive worrying as a means of dealing with the unpredictability of their condition in new environments. This in turn reduced their social participation, and curtailed their ability to adapt to new occupational transitions. This experience is consistent with the studies reporting the experience of living with a stigmatising illness reported elsewhere in the literature (Cunningham 1977; Fife and Wright 2000).

These findings have substantial implications for the provision of occupational therapy services. Considering the benefits of disclosing on the wellbeing of these participants, and the theoretical understanding occupational therapy has on the relationship between social engagement and wellness, occupational therapists are uniquely placed to promote disclosure in this population. Occupational therapists could do this is by working to tackle the social stigma of epilepsyby helping wider groups of individuals with impairments to develop a more positive self-image. Thus, new generations of individuals living with these conditions will have access to a more positive collective identity on which to construct an image of them and may no longer feel as stigmatised as previous generations (Kielhofner 2005; Zola 1993). One practical way occupational therapists can facilitate this proposed change is by creating peer mentoring programs within their existing support organisations (Kielhofner 2005). Reports

indicate that 73.7 % of young adults living with epilepsy experience depression and 36.2% experience social isolation to some degree as a result of stigma (Rafael 2010). These figures could be reduced significantly if effective peer-mentoring programs were developed and systematically integrated into epilepsy support organisations. Further, if funding to these programs is allocated in a substantial manner, it could significantly curtail the current expenditure on the psychological rehabilitation of this population (Freeman and Gayle 1978).

While this research is able to raise some important issues, it has some limitations which should be noted. The sampling of this study constitutes an important limitation. It is possible that those who responded to the invitation to participate in the study were those that were most open about their epilepsy. In this sense, the findings of this investigation may not be representative of the views held by other individuals who have this condition. However, the study has numerous strengths which include the nature of the inquiry and the research method employed. Using a qualitative mode of inquiry, this study explored the process of peer disclosure in young adults with epilepsy from the perspective of the individual. Another strength of the study rest on the researcher's effort to establish the criterion of trustworthiness in the research process.

Conclusion

This present study makes a significant contribution to the literature by highlighting the process of peer disclosure in young adults (18-25) with epilepsy. Weaving together lifespan theories (Ryan and Lynch 1989) and theories of occupational adaptation (Schultz and Schkade 1992), peer- disclosure can be conceptualised as an adaptive strategy evoked by young adults to help them assert greater control over their epilepsy in new environments.This motivation was reflected in the participants' process of selecting a recipient and also in their disclosure messages. The consequences of disclosure were primarily positive; participants described feeling safer, happier and more engaged in life. However, perceived stigma was identified as a significant barrier to disclosure.

A brief review of the epilepsy literature indicates that there to be a high prevalence of depression and anxiety in this population, arising as a result of perceived stigma (Rafael 2010). Given the beneficial effects of disclosure for well-being and social adjustment reported in this study, it is recommended that occupational therapists promote disclosure in this population by helping these youths feel less susceptible to stigma. They could do this by integrating peer-mentoring programmes that work towards the development of a positive

collective identity for persons with epilepsy within existing support organisations.This research by revealing the complex interdependence of systems that converges in disclosure process of young adults with epilepsy, offers an exciting framework upon which future studies could be based. Future studies could for example be developed to more explicably examine the identity-management process within the disclosure experience.

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APPENDIX A: RECRUITMENT LETTER

Dear Brainwave member,

My name is Karen Egan and as part of my Masters in Occupational Therapy degree I am doing a research project. I am interested in interviewing you to find out about how and when you decide to tell your friends you have epilepsy. In the interview I will ask you questions about what it is like to live with epilepsy, about your friendships, and about whether your diagnosis affects your friendships in any way.

The interview will last about an hour. The interview will be recorded, but the file will be destroyed as soon as I have typed up our conversation. You can decide not to answer questions if you are not comfortable and you can withdraw at any stage during the interview. I will send you a typed summary of your interview. If you want to make comments on that summary you can contact me. If you are interested, I can also send you the final research report in the spring of 2012.

Many people with epilepsy describe feeling uncomfortable about telling others they have this diagnosis. If you agree to be interviewed, all the information you share will be kept private and information that could identify you will be removed. If you agree to be interviewed, please email your first name and telephone number to the contact information listed below. I will call you to arrange an interview time and date that is convenient for you.
Thank you for your interest,

Karen Egan

_____

10000857@studentmail.ul.ie

APPENDIX B - INFORMATION SHEET

What is the study about?

This study is designed to better understand how and when young adults between the ages of 18 and 25 choose to tell others that they have epilepsy.

What will I have to do?

You will be invited to participate in an individual interviewing lasting about one hour. I will ask you questions about how and when you decide to tell people, especially your friends about having epilepsy. The interview will be recorded, but the file will be destroyed as soon as I have typed up our conversation. You can decide not to answer questions if you are not comfortable and you can withdraw at any stage during the interview. I will send you a typed summary of your interview. If you want to make comments on that summary you can contact me. If you are interested, I can also send you the final research report in the spring of 2012. Participation is voluntary. You can choose not to consent or to withdraw consent and stop participating in this study at any time.

What happens to the information?

The information that is collected will be kept confidential and stored on the researchers' computer with a protection password. The information will be anonymised and kept for a period of seven years, after which it will be deleted and/or disposed of sensitively. Healthcare providers may incorporate ideas drawn from your experience of disclosing and stigma management into their professional practice.

What if I have more questions or do not understand something?

If you have any questions related to any aspect of the study you may contact either of the researchers. It is important that you feel that all your questions have been answered.

Karen Egan
Masters Student
Occupational Therapy Department
10000857@studentmail.ul.ie

Dr. Nancy Salmon, Lecturer
Occupational Therapy Department
University of Limerick,
Tel (061) 234275
Email: Nancy. Salmon @ul.ie

If you have any concerns about this study and wish to contact someone independent, you may contact Alan Donnelly of the Education and Health Sciences Research Ethics Committee, Room E1003, University of Limerick, Limerick. Tel: (061) 234101.

APPENDIX C – CONSENT FORM

I, _____ [printed name] am aware that I am invited to take part voluntarily in the research project "Disclosure of epilepsy in young adult relationships".

I have been informed by the researcher, Karen Egan, of the following:

- That the purpose of the study is to better understand how and when young people with epilepsy tell others about this diagnosis.

- That I have the right to have all of my questions answered before, during and after the study.

- That my participation in this study will be audio recorded and I agree to this. However, should I feel uncomfortable at any time I can request that the recording equipment be switched off. I am entitled to copies of all recordings made and am fully informed as to what will happen to these recordings once the study is completed.

- That there is no obligation to participate in this study.

- That I am free to withdraw my participation at any time without having to explain or give a reason.

- That I am also entitled to full confidentiality. I will not be identified, nor will any private information about me be reported in any reports about this study.

_____   _____
Signature of participant   Date

_____   _____
Signature of researcher   Date

APPENDIX D: INTERVIEW SCHEDULE

I would like to ask you a few questions about having epilepsy, specifically your experience of disclosing your epilepsy condition to your friends. Please answer in as detailed as you can. There is no need to rush, so we can discuss any of the questions or topics at length. If you do not want to answer a question, or if you want to take a break at any stage, please let me know. If you have any questions during the interview please feel free to ask them.

(The following questions serve mainly as a guide and the researcher will adapt these to fit the interest of the participant and to accommodate new lines of research)

Part 1: Experience of living with epilepsy

Q) How did you first discover you had epilepsy?

- When? Where?

Q) What does a diagnosis of epilepsy mean to you?

Q) Overall, how, if at all has epilepsy affected your life?

- What kinds of difficulties, if any has it caused in life? Family? Friends?

Q) How do you feel about disclosing your condition to others?

Q) Under what circumstances or in what kind of situations do you tell other people about your epilepsy? In what situations do you not talk about it with others?

Q) Are there, or have there been, any periods or situations in your life when having epilepsy has been especially difficult or troublesome?

Part 2: Disclosing Epilepsy within existing friendships

Q) Tell me about your friendships before you found out you had epilepsy? Has anything changed in your friendships?

Q) When you first found out you had epilepsy who did you tell and what did you tell them?

Q) Can you tell me about a time you disclosed to a friend that you had epilepsy.

- Why did you tell him/her?

- What did you tell them?

- How soon did you tell them?

- What thoughts were running through your mind? Did you have any concerns about telling your friends you had epilepsy?

- How long did you think about telling him or her?

- What is it like disclosing as a male/female? Is it harder?

- How did he/ she respond? Was this what you expected?

- How do people relate to you after they find out?

- How did you feel after you told him/ her?

- How often do you discuss your epilepsy with your friend? In what contexts does it come up?

- Does your epilepsy factor in a lot of activities that ye do together?

- How aware are the friends ye socialise with of your epilepsy?

Part 3: Choosing not to disclose

Q) Can you tell me about a time you choose not to disclose to a friend?

- Why did you choose not to tell him? What did you consider to the risks?

- How do you think she would react? Did you consider this?

- Can you tell me about a time you were outed, How did you feel about this?

- In what ways was it different for you than your experience of disclosing?

Part 4: Wrapping up

Q) What advice would you give to someone who was considering disclosing their epilepsy to their friends?

Thank you.

APPENDIX E – 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   061-446786   Email: info@LKmentalhealth.ie

4. Pieta House offers counselling and support services to people experiencing a mental health crisis.
Contact Information
Website: http://www.pieta.ie/Index.html
Phone: 353 (01) 601 0000   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

List compiled by UL Occupational Therapy Department Unemployment study.

APPENDIX F –THEMES AND ASSOCIATED CATEGORIES

Assessing Disclosure Recipient	Managing presentation of Epilepsy
Having assurance of a positive response as a prerequisite for disclosure	Confirming self as a well identity
Fear of being pitied	Having a sense of self as distinct from epilepsy
Needing assurance of a positive response	Viewing respect as essential for recruiting ally
Viewing epilepsy as a threat to social identity	Normalizing epilepsy
Fearing differential treatment	Disclosing to maintain status as an honest person
Disclosing to close friends only	Casting epilepsy as less debilitating
Assessing reliability of ally	Understanding the public to have a limited awareness of epilepsy
Assessing trustworthiness of ally	Planning disclosure message
Construing concealment as a mechanism to avoid stigma	Emphasizing own competency within illness
Assessing risks and benefits of disclosing to ally	Needing to cast epilepsy as less debilitating to maintain support
Viewing diagnosis as personal information	Understanding accurate portrayal of epilepsy to lead to relational disintegration
Disclosing on need-to-know basis	Disclosing to offset identity threats caused by outing

Forging Alliances	Feeling more positive
Experiencing epilepsy as a source of oppression	Having a more balanced emotional experience
Feeling a loss of personal autonomy	Worrying less
Seeking to regain control	Feeling more connected to environment
Experiencing familial support as disabling	Coming to an acceptance of epilepsy
Being away from familial support networks	Feeling relieved after disclosure
Needing to create a new support system	Coping better with life changes
Recognizing nondisclosure as maladaptive	Feeling more positive about life
Understanding disclosure to create an obligation to co-manage epilepsy demands	Being more assured of physical safety
Viewing support to reduce the impact of epilepsy	Feeling emotionally supported
Expecting ally to take charge in the event of a seizure	
Educating ally on seizures	
Disclosing to create a forum for the discussion of concerns	
Co-concealing epilepsy	
Feeling trapped by worries	
Disclosing to foster closer bond	
Understanding disclosure to increase liking	
Understanding disclosure as an expression of trust	