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Barriers to Communication: The Views of People with Learning Disabilities with Epilepsy and Their Careers

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Abstract

People with learning disabilities experienced more health inequalities compared with the general population. Under-diagnosis is common among people with learning disabilities leading to unmet health needs compared with the general population. Numerous communication barriers have been reported in the literature but little is known regarding people with epilepsy and learning disabilities. The presence of epilepsy may further compound the communication needs of people with learning disabilities. The study investigated communication barriers between people with epilepsy and learning disabilities and carers.**Method**: Exploratory qualitative approach was adopted. Pictures and photographs were used when necessary to facilitate and elicit responses from participants. The interviews were recorded with participant consent.Analysis: The recorded interviews were transcribed verbatim and analysed thematically (Miles and Huberman, 1994).**Findings**: Service users and carers reported a range of communication barriers. These included; Stigma, discrimination, lack of knowledge, impairments and lack of alternative augmentative communication methods

Keywords: Communication, epilepsy, learning disabilities, carers, healthcare professionals.

Introduction

Communication with people with learning disabilities with epilepsy is vitally important to improved quality of care. People with learning disabilities are more likely to experience health inequalities compared with the general population due to communication impairments (Mastebroek, Naaldenberg, Lagro-Janssen, & van Schrojenstein Lantman de Valk, 2014; Ward, Nichols, & Freedman, 2010; Wullink, Veldhuijzen, van Schrojenstein Lantman - de Valk, Metsemakers, & Dinant, 2009). Communication challenges may result from a range of factors both internally and externally to the patient (Hemsley, Balandin, & Worrall, 2011). These communication difficulties may originate from the underlying impairments either physically or cognitively or may result from the individuals involved in the communication process (Hemsley et al., 2011).

It is claimed that communication is difficult for people with learning disabilities and the nurses who care for them (Hemsley, Balandin, & Worrall, 2012; Wullink et al., 2009). It is further argued that people with learning disabilities may have little or no spoken communication and may lack effective means to communicate with nurses and carers (Hemsley et al., 2012). However, people with learning disabilities in particular individuals with mild learning disabilities who reside in communities supported by carers/care workers may encounter greater communication barriers. They may want to actively participate in community services and thus may have different communication needs compared with individuals who are in hospitals or institutions.

It is generally believed that people with learning disabilities may require some form of Augmentative and Alternative Communication (AAC) such as communication boards and gestures (Hemsley et al., 2011) and Talking Mats (Murphy, 2007). In addition, the attitude, knowledge and the awareness of the communication partners' e.g. nursing staff, carers and healthcare professionals are crucially important as they may act as barriers or facilitators to communication

Furthermore, the presence of epilepsy may impact significantly on communication outcome. Epilepsy knowledge maybe a requirement for effective communication. Carers may need to have good understanding of epilepsy to enable them feedback information regarding seizures and medication. Misdiagnosis of epilepsy is reported higher among the general population and could be higher among the learning disabilities population due to communication difficulties (Chapman et al., 2011). In addition, epilepsy maybe a barrier to lifestyle choices for people with mild learning disabilities who live in the communities with the tendency to influence the communication needs for the individual.

Societal perceptions of epilepsy may impact on the individual negatively and how the individual engages with healthcare services regarding epilepsy. Association between stigma and epilepsy is widely reported (Bautista, Shapovalov, & Shoraka, 2015; Lee et al., 2016) and the presence of stigma may serve as a barrier to communication. Community-based adult with mild learning disabilities and epilepsy may want to lead an independent life as much as possible but the stigma may influence how they communicate and access community services. However, limited information is known regarding communication barriers with people with learning disabilities with epilepsy to identify barriers to communication.

Design

The study adopted a qualitative approach. Semi-structured interviews were administered to service users with epilepsy and mild learning disabilities. Pictures and photographs were used to facilitate the communication and to elicit responses.

Setting/population

The study was a community-based study. Participants were recruited through Quarries (epilepsy filed worker) and Community Learning Disabilities Teams (CLDT) within the locality.

Sampling

Purposive sampling technique was used to identify 28 people with mild learning disabilities and epilepsy and their carers. Nurses and consultant Psychiatrists were asked to identify people who fit the eligibility criteria of having a confirm diagnosis of epilepsy and learning disabilities, either receiving or eligible for learning disabilities services. Carers with less than one-year caring responsibility with the service user were excluded from the study.

Ethical approval

Ethical approval was granted by the Grampian Research Ethics Committee

Analysis

Transcript of the recorded interviews were produced. Transcripts were analysed following Miles and Huberman (1994) five processes of: familiarisation, identifying a thematic framework; indexing; charting and mapping and interpretation. Transcripts were read to identify main themes and categories. A coding frame was developed to reflect the study objectives (Young, Chesson & Wilson, 2007). Themes and codes were refined to reflect the main themes identified from the analysis.

Findings

Service users reported a range of communication barriers with carers and healthcare professionals. These include; limited knowledge and information, impairment, stigma, limited use of alternative augmentative communication methods

Stigma

This theme explores service users' and carers' perceptions regarding the impact of epilepsy on communication and their overall quality of life. In particular, it focuses on the impact of stigma, discrimination and anxiety/fear regarding epilepsy. Significant finding forms the study relate to the effect of stigma on communication. In this study, stigma was reported not only as impacting on quality of life but appeared to feature strongly as a barrier to communication. Service users and carers have consistently reported their views and experiences regarding epilepsy and the public perceptions of epilepsy. Service users in particular, shared the perception that once you are labelled with epilepsy people will not communicate with you and thus, you are better off if you are not identified as having epilepsy:

"You don't have to go round saying I have got epilepsy I have got epilepsy, I like to keep quiet about it, that is why I don't go to some of these meetings because as soon as people know that you suffer from epilepsy, they don't know you not that they don't like you but they don't communicate with you. People who have not got it, it is difficult for them to be with people with epilepsy and you suffer the consequences for something like that but you have not asked for it" Service user PP

Epilepsy was also described as having a significant impact on a family carer probably as a result of the more emotive relationship between carers and service users. This appears to be a reflection of the public discrimination against people with epilepsy and their carers:

"She was six years before she can start school because nobody will take her. She has even started the 'fits' at that time but all the time this was her main school, but the headmaster there has never ever, when I was in, call her by her name. I spoke with her and "… oh yes [headmaster] you are the mother of the epileptic" *that was quite unacceptable, even then these were some of the things we used to contend with" Family carer PB*

Limited knowledge and Information

A barrier that was consistently mentioned as impacting on communication related to limitations in carers' knowledge regarding epilepsy and medication. It was evident that to be able to communicate effectively, the understanding and the content of what to communicate was perceived as significant. Carers in particular, reported the need for some basic information relating to epilepsy to support their communication with the service user and to enable them to feedback appropriately to health professionals, for example on issues relating to seizure types:

"……is probably a gap in knowledge because I don't know obviously enough about as much as I should because

I work with her and more knowledge for what to look out for, just general knowledge of epilepsy would be ideal" Care worker PAb

"I do ask if he is taken his medicine but I don't understand epilepsy as we both have learning disabilities so if he takes a turn I don't know what to do" Family carer PF

"I don't understand epilepsy. I understand there are training programmes but I have not been yet" Carer PJ

"I asked and I was given a DVD video for a 'shot' and return it but it does not teach me anything. I would like to know more about epilepsy of what to do if he takes a 'turn'. What I need is someone to come up and sit down with me and tell me more about epilepsy is all I need but everybody is busy and I am not the pushy type of person" Family carer PF

These views were corroborated by service users:

"She would like to know more about epilepsy as I would like. And would she get help? That is what she needs to do, to learn something about epileptic fits" Service user PE

Lack of time to communicate

In addition, quality time was reported as a strong factor to every communication encounter in particular, involving service users. However, service users and carers both reported the inadequacy of time as impacting on communication although this appears to vary among different health professional groups:

"I feel is quite quick but am not a pushy person my personality is not to be pushy and forward. I felt the…. [doctor] *was like quick! out of the door whereas I spoke to… [nurse] and he was totally different and he explains everything, what to and what not to worry about" Care worker PQ*

"…..in the majority of the times they listen to you so far and chuck you out of the door with a piece of paper, you get this you get that. You see, the doctors nowadays seem to have less time than what they used to" Family carer PS

"I will say just maybe sometimes the doctors should listen a bit more but it boils down to how much time they have for each patient. Sometimes you feel especially with someone with learning disabilities if you are talking at appointments sometimes it takes longer than these ten minutes of allocation. And sometimes the person does not communicate that well and you find that it takes a bit longer and you are [carer] *a bit feel rushed" Care worker PO*

"Sometimes the doctors don't just want anybody else; you feel like they have no time for you to speak to, that is why you are holding things in. They don't want to listen, they are that busy, but even if you say I want to sit and have a word they want you out of the door" Service user PG

Limited Vocabulary

Also, carers in particular have commented on service users' vocabulary deficits. Claiming that technical words or jargon may results in poor communication. Service users may have limited vocabulary and may not understand the medical terms and this may hamper communication. Thus, there is a need to use plain and lay person language that can easily be understood:

"*They did not tell me but they have told her so she knew, but is difficult sometimes the medical words are a bit beyond her and if she wants to tell me sometimes she can't always remember the words" Family carer PB*

Moreover, there are other ranges of barriers reported. In particular, service users have reported their experiences of dealing with multiple care-workers as impacting on communication. Simultaneous changes to shifts patterns with different care-workers goes with different expectations. This does not only lead to communication mismatch or poor information but is also reported by service users as confusing:

"……..[care-worker] *does listen to me but then it is when you have more than one person dealing with different medications you get so confused Jerry, you know? You get like one person dealing with your morning ones then you get one person dealing with your lunch time ones and another one dealing with your tea time ones then you get another guy dealing with your bedtime. So is not the proper pattern you know. I get confused because sometimes my brain tells me one thing" Service user PT*

Discussion

The findings of this study suggest that people with learning disabilities are more vulnerable to a range of communication barriers when compared with the general population. These barriers are not only related to cognitive and physical impairments but also other society/community barriers. A significant number of these barriers originated from the individual and communication partners as well as society's perceptions of epilepsy. However, studies that investigated communication barriers to involve the views of people with learning disabilities are limited

An important communication barrier identified in this study related to how learning disabilities and epilepsy are perceived by the general public and the effect it has on the bearers of these conditions. People with learning disabilities in this study reported their experiences of stigma not relating to their disabilities but rather with the co-existing epilepsy. It is claimed that stigma bearers are often unable to challenge this negative phenomenon ascribed to them partly because they themselves accept the premises and the values which underlie their discredited social identity (Goffman, 1963). This may imply that people with learning disabilities have come to terms with and have identified themselves with their disabilities. They no longer see learning disabilities as a label but rather the stigma associated with the co-existing epilepsy.

Stigma has been reported in the literature (Bautista et al., 2015; Chesaniuk, Choi, Wicks, & Stadler, 2014) but often as an index of quality of life which may not relate to communication difficulties (Jacoby, 2002). However, in this study, service users have reported stigma as a strong barrier to communication. Service users reported their preference to hide their epilepsy as a mechanism to facilitate communication. They reported that when people get to know that they have epilepsy they will not communicate with them. Therefore, to ensure the continuity of communication, service users perceived it was best if people were not aware they have epilepsy.

Findings in this study reflected earlier studies which suggest that people with epilepsy frequently use concealment as a strategy for mitigating the negative impact of their condition in social encounters (Ablon, 2002; Goffman, 1963; Susman, 1994). Killnç and Campbell (2009) reported that people with epilepsy perceive stigma by feeling different from the rest of society, implying that they hide their condition as a way of managing the stigma and thus, the need to renegotiate their social identity. This study also demonstrated that carers perceived their experiences with epilepsy as discriminatory. This reflects some of the views held by society regarding epilepsy. In the past people with epilepsy were discriminated against because epilepsy was perceived to be associated with evil spirit. A study among ethnic minority group in England revealed that people still stereotyped epilepsy as caused by the devil (Ismail, Wright, Rhodes, Small, & Jacoby, 2005). Negative perceptions regarding epilepsy and seizures prior to diagnosis have also been identified as a contributory factor to stigma leading to reduced social interactions (Paschal, Ablah, Wetta-Hall, & Liow, 2005; Paschal et al., 2007).

Overall, these findings have implications for education. It is claimed that stigma may be created and nurtured by negative attitudes and statements by the family, children in school and the neighbourhood, doctors and other medical professionals as well as the general public including the media (Ablon, 2002). Family attitude can be particularly destructive. These behaviours and attitudes towards people with epilepsy are reported in the literature (Ablon, 2002). Research into people with epilepsy and their families indicated that those who cope well with the condition in most cases exhibit a commonality of biographical features and ideologies. The most important feature being unconditional family support and clear intra-family communication (Ablon, 2002); positive parental communication promotes confidence and empower the individual (Ablon, 2002).

Furthermore, it is claimed that one common factor that may explain these negative attitudes and behaviours from families is the lack of knowledge regarding epilepsy (Ablon, 2002). The public needs education regarding epilepsy in particular, the need to protect and encourage people with epilepsy to live a ‘normal’ life (KilInç & Campbell, 2009). It is argued that to ensure that people with learning disabilities are adequately supported there is the need to embrace both the principles of social inclusion and social capital (Bates and Davis, 2004). Social capital principles encourage the empowerment of people with learning disabilities through promotion of positive relationships whilst challenging society and media stereotypes through education (Bates & Davis, 2004).

The findings of this study also suggest carers’ perceptions regarding the abilities of people with learning disabilities to communicate as a barrier to communication. It could be assumed that carers with these stereotyped ideas may engage with the service user with the belief that they are incapable of communication. This assumption reflects the suggestion that disability arises from the social and physical barriers imposed by society rather than the inability of the individual to communicate (Van der Gaag, 1998). This is despite the current era when numerous research findings demonstrate that people with learning disabilities are capable of communication and expression of their views (Murphy, 2006) and can determine a research question (Young & Chesson, 2006). Yet people with learning disabilities are still perceived as incapable of expressing their views.

Furthermore, anxiety normally associated with the consultation encounter appears to impact on communication between a service user and some health professionals in this study. Graugaard and colleagues (2003) study in the general population reported on the importance of considering patient personality and emotional characteristics when evaluating patient’s communications with health professionals. It is argued that patient satisfaction with medical communication in a medical setting is not a simple measure of communication skills and how well the communication is structured; the anxiety associated with it and the patient’s ability to cope with the stress and anxiety should also be taken into account (Steptoe, Sutcliffe, Allen, & Coombes, 1991). Anxiety regarding medical consultation is common in the general population. Medical encounters are associated with many uncertainties, in particular, regarding the aetiology and prognosis of the condition. How the condition may impact on everyday lifestyle choices may lead to increased anxiety which may influence the communication encounter between patients and practitioners.

A significant barrier that emerged in this study relates to carers lack of knowledge regarding epilepsy and related issues. This finding is consistent with previous study findings (Elliott & Shneker, 2008; Saengsuwan, Laohasiriwong, Boonyaleepan, Sawanyawisuth, & Tiamkao, 2013). Service users are entitled to accurate information regarding epilepsy to enable them to exercise choices as consumers of health services, in particular, regarding treatment options (Brigo, Otte, Igwe, Tezzon, & Nardone, 2015). However, service users would only be able to make these consumerist decisions if they have the knowledge and detailed information regarding their health. Furthermore, carers spend significant amount of time with the service user. Therefore, it is imperative that carers possess basic knowledge and understanding of epilepsy and medications to adequately support the service user and also to facilitate communication. It may empower them to feedback information appropriately to health care professionals for example, in the event of seizures or missed medications. It is crucially important that the carer is able to adopt safety measures including the administration of first aid treatments during emergency situations.

An essential communication barrier reported by both service users and carers in this study related to the limited time spent with health care professionals. People with learning disabilities may take longer time to process information and to communicate compared with the general population. Therefore, the amount of time allocated for communication encounters with service users with learning disabilities can be a barrier to communication. This finding appears to be consistent with earlier studies which reported that people with learning disabilities and epilepsy require more consultation time with their health care professionals to discuss their treatments (Hemsley et al., 2012; Prinjha, Chapple, Herxheimer, & McPherson, 2005). Cook and Lennox also identified limited consultation time as a barrier to good quality care for people with learning disabilities (Cook & Lennox, 2000). Zivian et al., (2004) indicated that people with learning disabilities value having sufficient consultation time and the encounter not rushed, so that they can be listened to by health care professionals. However, this is likely to have implications on the individual health professional’s caseload and will impact on performance targets. Similarly, a study by Balandin et al., (2007) revealed that service users’ communication experiences were more positive when nurses had time to interact with them. This will enable a more effective engagement with the service user and allow in-depth exploration of the patient feelings (Hemsley et al., 2012).

In addition, carers expressed concerns regarding the service users’ lack of vocabulary as a barrier to communication. The prevalence of medical language over the use of everyday language has been reported in the literature (Fields, Freiberg, Fickenscher, & Shelley, 2008; Ong, de Haes, Hoos, & Lammes, 1995). The use of jargon and technical language by health professionals may lead to poor communication with service users. Service users in this study reported limited vocabulary and difficulty in understanding medical terms used by health professionals with consequent impact on their communication with health professionals and carers. Therefore, health care professionals have been encouraged to counsel in simple language understandable by people with learning disabilities (Zivian et al., 2004).

The study highlighted the need for alternative and augmentative communication methods to minimize any possible communication barriers between carers and people with learning disabilities. Technological advances have led to numerous forms of communication aids. User-friendly communication devices have been developed to include voice output devices for people with learning disabilities (Beukelman, 1998; Hourcade, 2004). The role of pictures and photographs to facilitate communication has been extensively discussed in the literature (Murphy, 2008). People with learning disabilities may have cognitive and communication impairments and the use of pictures may facilitate recall and elicit information spontaneously. Study findings indicated that, given adequate opportunities and effective methods, people with various learning disabilities and communication impairments are able to offer informative and reliable accounts of their opinions (Kroese, Gillott, & Atkinson, 1998). Visual representations such as pictures and photographs facilitate communication and reduce acquiescence and ‘recency effect’ (Kroese et al., 1998).

Carers/caregivers are encouraged to use augmentative and alternative communications to meet the needs for people with learning disabilities (Hong, Ganz, Gilliland, & Ninci, 2014).

Furthermore, service users and carers also associated some communication barriers to the underlying impairments of both the service user and the carer. These impairments may be both physical and cognitive. Service users described the difficulties involved in physically articulating the words. Cognitive and memory loss may also contribute to poor communication. One carer also relates her communication difficulties to her own impairments (learning disabilities) which she perceived acted as a barrier to her communication with the service user.

Conclusion and implications for practice

Communication between people with epilepsy and health and social care professionals are multifactorial. Reported barriers include: knowledge and information regarding epilepsy, the impairment, stigma and perceptions of epilepsy and lack of augmentative and alternative communication methods. Overall, these findings suggest the need for education regarding epilepsy and communication training for nurses and carers. In particular, stigma of epilepsy appears to impact significantly on communication and reflect the need for health promotion and public education.

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