

Short Communication

The Views of People with Learning Disabilities with Epilepsy Communication with Carers and Healthcare Professionals

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Abstract

Effective communication plays a crucial role in the management of people with learning disabilities with epilepsy. The literature suggests that poor adherence to treatment is higher among people with learning disabilities. This is attributed to a range of factors including communication difficulties, poor information provision and cognitive impairments. Effective communication has both therapeutic and health promotion functions. This study aimed to solicit services users and carers experiences and perspectives regarding communication with health and social care professionals.

Methodology: The study adopted qualitative exploratory approach using in-depth interviews and communication diaries. It was a community-based study involving people with learning disabilities with epilepsy in the North-Eastern part of Scotland. Sample size consisted of 28 community-based adults aged 16-50. Informed consent was obtained from the participants and ethical clearance was given by the Grampian Research Ethics Committee.

Analysis: Data-driven analysis was applied based on Systematic Text Condensation to produced descriptive findings

Findings: Analysis revealed that services users and carers views and experiences of communication with healthcare professionals were largely negative. They reported that they were not being listened to by healthcare professionals although this report varied with individual healthcare professionals and also with the professional discipline. Service users reported that the quantity and quality of information obtained from healthcare professional were limited.

Conclusion: The findings suggest that effective communication with people with learning disabilities with epilepsy requires that healthcare providers adopt a listening approach and involve service users as consumers of healthcare services with the rights to information which may improve quality of life.

INTRODUCTION

It is estimated that people with learning disabilities constitute about 2% of the general population [1] and this translate to about 7-30 people with mild to severe learning disabilities in each general practice across the UK [2]. Epilepsy is one of the most common enduring neurological conditions affecting people with learning disabilities. Estimates are that up to a third of all people with learning disabilities have epilepsy and up to a quarter of all people with epilepsy have learning disabilities [3] and the

prevalence increases with increasing severity of the disability [3-6]. Further estimates are that epilepsy is 20-25 times more common among people with learning disabilities compared with the general population [7]. Other studies suggests that people with learning disabilities are about 20-30 times more likely to have seizures compared with the general population [8,9]. Mortality rates in people with learning disabilities and epilepsy are said to be five times higher compared with the learning disability population overall [6,10]. Furthermore it is claimed that about 30% of epilepsy related deaths occur among people

with learning disabilities [11]. Higher rates of mortality among people with learning disabilities with epilepsy are associated with poorly controlled seizures. This may reflect non-adherence to medication, poor communication and information provision and limited understanding of treatment regimens [12]. This may be attributed to communication difficulties, cognitive decline and limited service user involvement in treatment of their condition. Effective communication with people with learning disabilities and epilepsy has both the therapeutic and health promotion functions including psychosocial benefits [13]. Stigma is widely reported to be associated with epilepsy [14]. Certain psychosocial traits are reported to be associated with felt stigma among people with epilepsy [14]. For effective management of people with learning disabilities with epilepsy, there is the need for multidisciplinary communication involving service users, carers and healthcare professionals. People with learning disabilities have long been perceived as incapable of communicating their needs. However, numerous findings suggest that people with learning disabilities are more than capable of expressing their views regarding the services they receive [15-18]. This informed the need for this study to investigate communication exchanges between service users, carers and healthcare professionals.

Methodology

This study adopted qualitative exploratory research methodology approach [19]. Overall, the naturalistic inquiry paradigm is underpinned by two key assumptions. Firstly, people cannot be separated or removed from their natural environment physically, socially or culturally. Humans constantly seek to influence their environment and are in turn influenced by it; behaviour can be explained in terms of the interaction between individuals and the environment [19]. Secondly, it is not possible to observe the personal meanings and perspectives that guide our human behaviour within a given context. There is always an interpretive element between people and their environment [19]. This means that each person might behave differently in a given set of circumstances and unique experiences and knowledge are brought to the situation. This study involves community-based adults who live and interact with their natural setting and it may not be possible or it may be inappropriate to detach their constructions of realities and meanings from the environment in which they are derived.

Settings

The study was conducted in collaboration with the North of Scotland Managed Clinical Network for Epilepsy. It was a community-based study and the target population were people with learning disabilities and epilepsy in the North-Eastern part of Scotland.

Sampling and data collection

Purposive sampling of 28 community-based adults aged 16-50 who were either receiving or eligible for learning disabilities services were sampled. Participants were recruited through the community learning disabilities teams within the study locality. Participants who meet the inclusion criteria were nominated by the learning disabilities teams comprising, nurses, epilepsy fieldworkers and consultant neurologists. Following this,

informed consent was sought from the individual participants. The inclusion criteria included; a confirmed diagnosis of epilepsy with learning disabilities, either receiving or eligible for learning disabilities services, able to communicate verbally and can give informed consent.

Semi-structured interviews using schedules were used to collect data from participants (service users and carers). Photographs, signs and symbols were used when appropriate to keep the interview focused or to elicit responses. Participants were interviewed at a place convenient for both the researcher and participants. This was either at participant's home, surgery or at the day-care centre.

Demographic characteristics showed that 17(61%) of the participants were females while 11(39%) were males. Majority 22(79%) of them preferred to be interviewed at home and the rest 6(21%) were interviewed either at the GP surgery or Day-care centre. Informed consent was obtained from the participants. Ethical clearance was granted by the Grampian Research Ethics Committee.

Analysis

The data were analysed following [20] four processes of Systematic Text Condensation (STC). The four phases characterising this approach are:

Total impression - from chaos to themes: Although data collection and analysis occur concurrently, all the interviews were meticulously transcribed verbatim after each interview was completed by the researcher, including the non-verbal signals and gestures [21]. The transcripts were thoroughly read over several times in order to allow for familiarization with the data and to gain a fuller understanding of the data as a whole. What participants tell me that is relevant to the phenomena communication with carers, health professionals and with service users? Does it relate to quality of information provision, involvement, listening, understanding, epilepsy, medication? As the analysis stage is considered as a team process, the transcripts were also read by my supervisory team. This was not to gain consensus but to create a wider analytic space. At this stage we try to 'bracket' our views and preconceptions but maintaining an open mind as much as possible [20]. Each researcher lists his or her preliminary themes and negotiates confluent and divergent issues. During the reading processes, key phrases, concepts are noted with a marker because they evoke or prompt an idea. Following this, the meanings of passages, words and concepts are tentatively interpreted by the researchers and noted along the margins of the transcripts (Appendix 1b)

Identifying and sorting meaning units - from themes to codes: The text was thoroughly examined line by line to break it to meaning units i.e. different aspects of the meaning of the phenomena communication with carers and healthcare professionals [22]. Meaning unit could vary from word, sentence to a paragraph and was delineated when there was a change of meaning in the description of the phenomena provided by the participant. Meaning units were then coded which involves identifying, classifying and sorting meaning units which are potentially related to previously negotiated units. Coding implies decontextualisation, temporarily removing parts of the text from

their original context for cross-case synthesis with themes as road signs [20]. Following this meaning units are identified and mark them with a code i.e a label that connect related meaning units into a code group (Appendix 1a)

Condensation - from code to meaning: This stage of the analysis involves abstraction of the meaning units within each of the code groups established in the second stage. Empirical data are reduced to a decontextualized selection of meaning units sorted as thematic code groups across individual participants. Following this, meaning units of the actual code group are sorted into few subgroups depending on the research objectives which were to investigate the communication outcomes between services users, carers with healthcare professionals

Synthesising - from condensation to description and concepts: In this final stage of the analysis data are reconceptualised, putting the pieces together again. Synthesising the contents of the condensate, we develop descriptions and concepts, providing credible stories that make a difference by elucidating the study objectives [20]. Starting from the condensate and quotation from each subgroup within a code group we develop a story about the phenomena grounded in the empirical data as an analytic text presenting the most salient content and meaning [20].

This approach was chosen and applied consistently to analyse the data (service users and carers interviews data) to explore participants' experiences and views regarding communication with health and social care professionals.

Findings

This section presents the findings from the service users and carers' views and experiences of communication with healthcare professionals. Service users and carers views and experiences regarding listening and understanding were reported as largely negative. They reported that they were not being listened to by healthcare professionals although this report varied with individual healthcare professionals and also with the professional discipline. Nurses were perceived on the whole as more listening than doctors in most cases. With regard to quality of information provision, service users reported that the quantity and quality of information obtained from healthcare professional were limited.

Listening and understanding

A positive observation was that service users and their carers are able to transact communication effectively with each other regarding listening and the understanding of information as demonstrated by the quotes below:

"She listens to me, she will sit down, listen and she will ask me questions" Service user PI

"Is easy, even though she comes from [location] and I come from different part of the world we do understand each other" Service user PE

"He is the person who knows what I am going through, he does listen. I see that sometimes other people are not bothered listening to me even though we have meetings up here" Service user PG

And also, service users are able to disengage from

communication and decide when to listen and when not to listen to:

"She will definitely let you know what she is talking about, if it is something she does not want to hear is quite difficult to get through to her because she thinks I am just trying to 'have a go' at her rather than help her. She just listens to what she wants to hear" Family carer PB

However, service users in this study have expressed specific concerns relating to engaging with multiple care workers as affecting the quality of communication. They described their experiences of interacting with multiple care workers as confusing and thus, impacting on their understanding:

".....[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

Overall service users and carers views and experiences of communication with health care professionals regarding listening and understandings were perceived as negative. Both service users and carers have persistently reported that they were not being listened to by health care professionals. However, this was reported to vary with the individual's health care professional and also with the professional discipline:

"Nurses are more listening than the doctors; they are more 'geared up' [listening] to what you are saying than the doctors. Some of the doctors don't just listen, is just flowing over their heads" Service user PE

"I think the doctor was not probably listening to me. There was one doctor I think last week I have been on medication for my depression and one doctor tries to reduce it, but on Friday I have to go past and get it put back to normal" Service user PC

".....we used to have one doctor called [name] he used to listen and listen and listen. In the majority of times they [doctors] listen to you so far and chuck you out of the door with a piece of paper and say you get this and get that" Family carer PS

".....they [doctors] only listen to what they want to listen and that is the end of story" Family carer PS

Quality time

A recurrent concern that was expressed by both service users and their carers related to the quality of time with health care professionals. Service users and carers reported they would value more time with healthcare professionals to enable them engage more effectively:

"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

"I did feel that I went down to see the doctor, I felt she was like

quick out of the door and I spoke with [nurse] and he was totally different" Care worker PQ

"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 to them 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 feel a bit rushed" Care worker PO

Quality of information provision

A common theme expressed by service users related to the quality of information received from health care professionals. Service users reported that the quantity and quality of information obtained from health care professionals was limited. However, this was also reported to vary among individuals and also with the health care professional groups. Service users will value more time with healthcare professionals to enable them express their concerns:

".....I get more information from a nurse than I would from a doctor, they go about it in a different way, they discuss first what is wrong with you as the doctors will tell you what is wrong with you" Service user PE

"Doctors are funny people, nurses get down to the 'nitty gritty' and help you, where doctors don't" Service user PP

DISCUSSION

The findings demonstrate that service users in this study have good insight regarding communication with their carers and health care professionals, and the impact of communication on the management of epilepsy. Service users in this study appeared to have good insight regarding the outcomes of communication with carers and health care professionals. The findings suggest that effective engagement is viewed as a dialogue between the health provider and the service user which requires the exchange of information between the patient and the health care professional rather than just an information seeking process [23].

Furthermore, it was evident from service users and carers experiences in this study that effective engagement embodies certain elements which are crucially important to the communication encounter. The effectiveness of the engagement as reported by service users and carers in the study is dependent to a great extent on whether the parties involved in the communication process do have time to listen to each other, the quantity and quality of information provided by health care professionals, and the time allocated for the communication encounter to enable service users input in the communication. Service users and carers reported dissatisfaction regarding their engagements with health professionals and their experiences of communication reported are largely negative although this varies among different professionals.

Listening

Although this was reported to vary among different health care professionals, service users and carers in this study perceived they were not being listened to by health professionals and this

may be having significant impact on quality of life. It is asserted that when patients are being listened to it has a therapeutic effect and is regarded as a healing process [2]. Other studies suggest that engaging actively in a communication encounter is beneficial and associated with positive outcomes [25]. The significance of listening as an integral part of the communication process has been highlighted previously in the general population [24,26]. Other findings suggest that in clinical practice patients often contribute very little to the consultation apart from answering direct questions [25]. A study by [27] reported that people with learning disabilities want to be treated as adults and prefer to engage face-to-face with their healthcare providers. It is claimed that communication is at least a two-way process in which both parties have the responsibility to making the communication encounter a success [28]. Previous studies argued that people with learning disabilities are more vulnerable to suggestions and are more likely to acquiesce [29]. Therefore, to make the most out of a communication encounter, consideration must be given to good listening skills. This ensures that the message is understood by the parties involved. It is posited that if you listen carefully to the patient, they will tell you the diagnosis [24].

Active listening to patients may involve giving undivided attention to the patients, and listening to both the content and emotion, and responding to feelings. Arguably, 'empathetic listening' is considered as one of the essential ingredients of good clinical practice [24]. Furthermore, it is claimed that active listening includes a set of non-verbal skills that signifies to the patient that the health professional is listening attentively, these include; leaning forward, being silent, using smiles and nodding to encourage further disclosure [30]. In particular, service users in this study demonstrated a degree of cognitive and communication impairment and may require more time to be able to process information and to elicit the required information. This needs to be taken into consideration as part of providing and creating opportunities for people with learning disabilities to communicate [31].

Quality time with health care professionals

Quality time with health care professionals was perceived as an essential aspect of engagement; however, this was reported by participants to be lacking. Good consultation time is regarded as an indicator of quality health services delivery [32]. Service users and carers in this study reported the need for more consultation time with their health care professionals to discuss any health concerns they may have but often this is not the case and service users in this study reported they are not offered the opportunity by some health professionals in particular, some doctors. These findings concur with previous studies in the general population [33]. People with learning disabilities have reported difficulties engaging in communication when the encounter is rushed [27]. This may be related to cognitive and communication impairment. Thus, people with learning disabilities may need more time to communicate compared with the general population [34]. Also, research findings suggest that doctors who consult more slowly are likely to have consultations that include important aspects of care and are more likely to include lifestyle advice and health promoting activities compared with those with limited consultation times [32].

Quality information provision

Service users in this study have reported on the limited and poor quality of information they receive from health care professionals. Service users value involvement and information sharing with their health professionals. They reported they need detailed information regarding their health including the causes and treatment options in order to reduce anxiety and improve quality of life. However, information provision was perceived to be limited among some health care professional groups. This finding is consistent with previous studies in the general population which suggest that patients perceived their information regarding epilepsy as poor, thus impacting on their understanding [35]. Poor health communication is likely to aggravate seizure control and will impact significantly on the psychosocial well-being of the individual and their families. In particular, community-based adults with learning disabilities are entitled to full and accurate information regarding their health care and may want to adopt a more consumerist approach when seeking information from health care professionals.

Moreover, the transition from the medico-biological concepts of disabilities to the bio-psychosocial approach of disabilities requires a paradigm shift which involves the patient and psychological wellbeing. Arguably, the paternalistic models of communication where the patient is a passive receiver is now considered to be outdated, paving the way for social models that encourage patient participation in decision making [36,37]. However, this was not reflected in the findings of this study. The use of medical models of communication in clinical practice appears to be dominant in this study. It is argued that health care professionals may adopt the 'experts' approach and focus on curing the condition for the individual however, service users may be interested in information being discursive and sharing the information with them so that they can input in care management decisions [38]. However, this is reported to be lacking in this study. Service users and carers in this study want to be actively involved in their health care so that they can express their views instead of being passive recipients of information from health professionals:

".....I get more information from a nurse than I would from a doctor, they go about it in a different way, they discuss first what is wrong with you as the doctors will tell you what is wrong with you"
Service user PE

These findings are incongruent with the philosophy of patient-centred communication which is based on the assumptions that health care professionals must modify their ways of communication by: helping patients feel understood, through inquiry into patients' needs, views and expectations [39]. This involves listening to the psychosocial aspects and expanding patient involvement in the management of their health needs [39]. Service users reported they want information regarding their health to be fully discussed with them to enable them to understand and make decisions which are consistent with their daily lives.

Nevertheless, the quality of the information provision is dependent on how accessible it is to enable the service user to understand and contribute to the encounter. The information

needs to be tailored to the level of understanding of the consumer, particularly for people with learning disabilities who have cognitive and communication impairments and limited recall [40]. It is argued that information for people with learning disabilities needs to be well presented in order to promote understanding [41]. Furthermore, it is claimed that people with learning disabilities have low literacy skills compared with the general population and are also known to have limited vocabulary [40,42]. Epilepsy and medication may involve the use of technical and medical terms beyond the understanding of service users and their carers [40]. Therefore, people with learning disabilities may need information in a clear and simple language free from any jargon to enhance understanding [43]. Studies reported that non-compliance is very high when patients are unable to read and understand basic written medical instructions [43]. Other causes of non-compliance have been reported as related to patients' inability to remember the details of recommendations made to them [44]. However, this could be higher among people with learning disabilities due to cognitive impairment.

CONCLUSION AND IMPLICATIONS FOR PRACTICE

Service users in this study have strong insight regarding effective communication with carers and health professionals. Both service users and their carers regarded 'engagement' as a strong predictor of effective communication. However, service users' experiences of engagement with health professionals are primarily negative characterised by the influence of the medical models of communication in clinical practice. Specific concerns related to: listening and understanding; quality time and quality information provision. The findings service user involvement is an integral part of managing their healthcare needs. In particular, community-based individuals with learning disabilities and epilepsy may wish to be more involved through communication as adults to facilitate concordance with treatment.

Limitations

This is a qualitative study and no attempt is made to generalise the findings.

Participants of the study in particular, service users were nominated by their healthcare providers which arguably could introduce biases in the selection process. However, individuals who fit the inclusion criteria we nominated on the basis that they may be willing to participate but not necessarily automatic that they will participate and indeed some were nominated but declined to participate.

The studies focus on only the views and experiences of service users and their carers to the neglect of the healthcare professionals although this may give a fuller understanding of the phenomena.

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