Research Article

Communication Strategies: The Views of People with Learning Disabilities with Epilepsy and Their Carers

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Abstract

The aim of this study is to investigate strategies used by people with learning disabilities and epilepsy to meet their communication needs with carers and health and social care professionals. Communication in healthcare setting is of crucial importance to quality of life of the individual. Effective communication is a key determinant of patient satisfaction, compliance and recovery.

Methodology: The study adopts a naturalistic inquiry approach using semi-structured interviews. The population was made up of adults with learning disabilities with epilepsy and their careers.

Analysis: The data was analysed thematically using a framework approach which yielded descriptive findings

Findings: The study produced a range of communication strategies including behavioural strategies, modified communication environment and organisational strategies as tools for communication.

Conclusion: The findings of this study indicated that people with learning disabilities adopted a range of communication strategies to ensuring that the communication with carers and healthcare professionals is successful.

INTRODUCTION

Communication is a complex multidisciplinary concept and has been variously defined. It consists of a complex composite of verbal and non-verbal behaviours linked together for the purposes of sharing information, messages, ideas and feelings (Arnold & Boggs, 2003; Hourcade, 2004; Rogers & Kincaid, 1981)[1,2,3]. Communication in the health care setting is of crucial importance to the quality of life of the individual (Hemsley, Balandin, & Worrall, 2011; van der Gaag, 1998)4,5. Effective communication is largely recognised as a key determinant of patient satisfaction, compliance and recovery (Chant, Jenkinson, Randle, & Russell, 2002)6. It is argued that effective communication can boost patient recovery whereas poor communication can be distressing to the patient and health and social care professionals (Hemsley et al., 2001)7. However, people with learning disabilities, irrespective of their levels of impairments, are more likely to encounter some form of communication difficulties compared with the general population (Hemsley et al., 2011; Kelly, 2002)4,8. McQueen et al estimated that 66% of people with learning disabilities have

some form of communication difficulties (McQueen et al, in:van der Gaag, 1998)5. A survey in a social educational centre reported 81% of people with learning disabilities required support with their communication, 9.5% of these needs being non-verbal and 5.9% demonstrating low understanding (Law and Lester, 1992 in:Bartlett, 1997).

It is further claimed that communication with adults with learning disabilities is more challenging compared with the general population (Hemsley et al., 2011)4. These communication difficulties are usually conceptualized to originate from the person with the disabilities (McConkey et al, 1999). Thus, researchers mostly focus on soliciting carers and health care professionals views on how to remediate these communication shortcomings (McConkey, Morris, & Purcell, 1999)9. Furthermore, it has long been assumed that the communication style of adults with learning disabilities are less susceptible to change and therefore any modifications to communication are more likely to be driven by the more able persons who are more adaptable to meeting the communication needs of the individual (Chatterton, 1999;

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McConkey et al., 1999)10,9. Bartlett & Bunning, cited in Bartlett (1997)11, commented on the need for staff to recognise and make adaptive changes to meet the communicative 'acts' of service users. However, other schools of thought forwarded the view that everyone can communicate; even people with severely impaired communication disabilities are able to communicate quite effectively if given the right support and facilitation (Kovarsky et al, 1999 in:Hemsley et al., 2001).

Overall, communication research regarding people with learning disabilities focuses largely on meeting and developing health and social care staff communication needs and skills (Balandin, Hemsley, Sigafoos, & Green, 2007; Bradshaw, 2001; Graves, 2007; Jones, 2000; McConkey et al., 1999; Pointu & Cole, 2005; Purcell, McConkey, & Morris, 2000)12,13,14,15,9,16,17. To a significant extent, communication studies regarding people with learning disabilities are more common among children populations (Bradlow, Kraus, & Hayes, 2003; Horowitz, 2006; Kaiser, 2007; Wetherby, Watt, Morgan, & Shumway, 2007)18,20,21. Also, studies that include adults are based on institutional or residential settings and mostly include people with severe to profound learning disabilities who have more complex communication needs (Bradshaw, 2001; Cegala, 2006; Jones, 2000)13,22. However, community-based adults with mild learning disabilities may have different communication needs and expectations but this focus has received little attention. In particular, at the time of writing, little is known regarding studies which investigated the views and experiences of people with learning disabilities and epilepsy regarding communication. In addition, studies that investigated the individuals' perspectives regarding epilepsy often fail to distinguish the learning disabilities from the non-learning disabilities populations (Bautista, Glen, & Shetty, 2007; Chappell, 1992; Chappell & Smithson, 1998; Elwyn et al., 2003; Ismail, Wright, Rhodes, Small, & Jacoby, 2005; Paschal et al., 2007; Poole et al., 2000; Räty, Söderfeldt, & Wilde Larsson, 2007)23,24,25,26,27,28,30. The service users with learning disabilities views regarding communication are often not reported or investigated. In particular, the presence of epilepsy can impact significantly on communication. Therefore, an important aspect of communication is often missing. The literature suggests a high prevalence of communication difficulties among people perceived as having 'challenging behaviours'. However, 'challenging behaviour' has a communication function (Chiang, 2008)31. Ferris-Taylor (2003) claims that challenging behaviour may be an attempt to communicate a message. Poor communication may also result in maladaptive behaviours that pose a challenge to health care professionals and carers (Ouellette-Kuntz, 2005). It is argued that professionals working with people with learning disabilities should be aware of maladaptive behaviours and learn to recognise a range of behaviours as possible forms of communication, thus adopting a generous definition of communication (Kelly, 2002)8. This exploratory study sought to investigate people with learning disabilities with epilepsy views regarding communication with health and social care professionals.

Methodology

The study adopted a naturalistic qualitative research methodology approach (Lincoln & Guba, 1985). Semi-structured interviews were administered to participants. The interview data was supplemented by carer communication diaries.

Setting

The study was conducted in collaboration with the North of Scotland *community learning disability teams*. The target people were individuals with learning disabilities and epilepsy and their carersin the North-East of Scotland.

Sampling and data collection

Twenty-eight people with learning disabilities and epilepsy were purposively sampled. Interviews were recorded with the participant consent. Informed consent was obtained from the participants. Ethical clearance was granted by the Grampian Research Ethics Committee.

Analysis

Thematic framework analysis was applied to process both the interview data following the five processes of Familiarization, Identification, Indexing, Charting and Mapping/interpretation (Bryman & Burgess, 1994) which produced descriptive findings.

Findings

Key findings describe communication strategies of communication approaches service users adopt to facilitate communication with each other and also with health care professionals. Service users and carers have reported ranges of strategies of communication to ensuring that communication is effective.

Individual styles of communication

Both service users and carers have reported their awareness of what and how they adopt various styles as strategies to communicate with each other:

"If I am talking to my friends is my usual "banter" but usually softer when talking to her [carer]*" Service user PE*

"I get confused about sometimes and she [carer] *explains it in a different way and I will understand" Service user PN*

"We try to make it as adult as possible but we have also got the level of understanding to try and clarify things or simplify things as much as we can. It is always a difficult one she is an adult but there is a learning disability and at times we need to sort of simplify things" Carer PL

Organisation and planning

Advanced planning was widely viewed by carers as an important strategy for any communication events or sessions with service users. Planning involved ranges of activities as suggested by carers.

Firstly, carers have found it useful to prepare a rota so that service users become familiar with the routines and are aware of what needs to be done and at what time and thus will facilitate communication:

"She knew by the rota that it was her turn to use the washing machine" Carer Diary MW

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Communication environment

Secondly, carers forwarded that identifying a suitable communication environment is an essential component of any successful communication. When a conducive environment is selected that is free from any distraction it may promote concentration and thus enhance communication with the service user:

"We also went out to a local café' for a bit of uninterrupted planning time" Carer Diary MW

Thirdly, it was widely reported by carers that service users may work slowly or communicate at a slow pace. Therefore, service users may require sufficient time to work at their own pace and this should be taken into consideration when communicating with service users:

"I might start earlier to give her more time" Carer Diary MW

"...... [User] likes being left to complete things in her own time" Carer Diary MW

"....Trying not to rush her" Carer Diary GS

"By keeping a calm manner and doing the shopping at [User] pace" Carer Diary AJ

Behavioural strategies for communication

Furthermore, service users and carers also reported how they adopt certain behavioural strategies including intimidation as means of communication to ensure they are listened to; and thus to effect communication with their health care professionals:

"......I do but I think I do frighten them. The way I speak to them; you would listen either or you would not do that with me like, I would sit here for nearly a day and won't let anybody out and a lot of folks don't like it. They are really, really scared of me, that is the only way they can listen" Service user PG

"If she [service user] is not getting her way, certainly in the past she has used seizures and she can fake them fairly well" Carer PL

"If you appear to be assertive and a no nonsense sort of person you get listened to; but if you are subservient and look like you will accept a lesser service then that is what you are given" Carer PW

DISCUSSION

The findings from the study indicate that communication with people with learning disabilities involves a range of strategies. Therefore, to ensure communication is effective, there is a need to deploy the appropriate communication strategies. Both service users and carers in this study have described various communication strategies they employ when communicating with each other and also with health care professionals. Service users in particular have reported different styles of communication as strategies to ensure the communication is a success with their carers.

The literature is populated with studies regarding communication strategies with people with learning disabilities however, little is known regarding service users' contributions. The need for carers and care-workers, to modify their styles

of communication has been well reported in the literature. Studies have commented on the need for carers and health care professionals to recognise and make changes to meet the communication 'acts' of service users (Bartlett and Bunning, 2000). This study revealed how service users and carers adapt specific communication strategies they perceived to promote communication. This finding contradicts previous studies indicating that carers in particular, often fail to adapt their communication strategies with the service user with greater parts of the communication 'acts' falling outside the understanding levels of the service user (Bradshaw, 2001, Purcell, 1999)13,9.

A significant finding in this study related to certain behavioural strategies employed by service users and their carers to communicate with health care professionals. A service user reported a behaviour such as 'intimidation' as a reflective strategy to effect communication with health care professionals. Thus, finding is a reflection of the adage that 'when persuasion fails force must be applied'.

The use of behaviour as a form of communication is not a new finding but in fact has been well reported in the literature. Service users who may be unable to communicate their needs or have their needs denied may resort to specific behaviours in order to express their needs. 'Challenging behaviour' has been given significant highlight as a form of communication difficulty in earlier studies (Sigafoos, 2000, Kevan, 2003). It is asserted that sudden behaviour changes are always a communication of a particular need or distress (Lennox &Eastgate, 2004). An estimated 10-15% of people with learning disabilities demonstrate some forms of challenging behaviours (Emerson et al., 2001). However, 'challenging behaviour' is said to be 'socially mediated' aimed to access or escape from social attention (Kevan, 2003, Emerson, 1995, Bailey, 2006). It is claimed that people with learning disabilities see challenging behaviour as an effective communication tool when other more conventional forms fail (van der Gaag, 1998)5. Challenging behaviours are reported more commonly in people with more severe communication difficulties whether receptive or expressive in nature (Emerson, 1995). However, people with mild learning disabilities may demonstrate verbally expressive challenging behaviours. Community-based adults with learning disabilities may want to lead independent lives, and have their views respected; however, failure to express or articulate their needs verbally may lead to frustration and the individual may resort to behavioural strategies to communicate their needs.

Furthermore, the findings in this study suggest that behaviour was not only a tool recognised by service users as a strategy but also by their carers. Assertiveness was perceived by a carer as a behavioural strategy used to effect communication with health care professionals. Although assertiveness has been reported in the literature as a strong predictor of information-seeking desire, little is known regarding carers' assertiveness as a behavioural strategy to communicate. It is claimed that assertive adults are more likely to seek detailed information regarding their health (Braman & Gomez, 2004). This implies that carers who want to express their views but feel oppressed or who want to resist the dominance of health professionals may resort to assertiveness in order to be listened to and have their views regarding the service

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user expressed. However, this has the potential for conflict. The majority of service users in this study reported they are self-caring and may not want to involve the carers or have the carer advocating for them in particular, regarding health management.

In addition, carers in this study have also used 'planning' as a strategy that may enhance communication with service users. Planning appears to be congruent with creating opportunities for the individuals to communicate. Adequate preparation prior to consultations is reported to have positive outcomes (Zivian et al., 2004). Involving people with learning disabilities in communication depends to some extent on the abilities of others to create effective opportunities for communication to take place (Sigafoos, 1999). For example, it was evident from the content of the carer communication diaries that communication with the service user may work better when sufficient time is made available for the service user to work at their own pace, so that the encounter is not rushed and thus service users may be able to contribute.

The findings in this study also suggest the communication environment was used as a significant component of communication strategies. Generally, it is claimed that certain features of the environment in a health care setting may impact on the application of communication skills and the ability to communicate effectively (Chant et al., 2002)6. It is claimed that communication involves interaction between the communication partners, and the environment influences the overall communication process (Park & Song, 2005). Therefore, it is essential that a suitable environment that stimulates communication and improves concentration is considered when planning to engage in communication with service users. It is further argued that one way to identify opportunities for communication is to conduct an assessment or audit of the environment for example, by using an 'ecologic inventory model' (Sigafoos, 1999). By assessing the communication environment to eliminate environmental factors that may act as barriers to communication (Sigafoos, 1999). The quality of the communication environment is also reported to be linked with reducing challenging behaviour (Hastings, 1997). Numerous environmental factors are known to impact on communication. For example, a study by Park and Song, (2005) reported ranges of environmental factors as barriers to communication. These include; noisy environment, being in unfamiliar situation or location and the absence of a caregiver.

CONCLUSION AND IMPLICATIONS FOR PRACTICE

It was evident in this study that service users and carers are not only capable of communication but can evaluate the communication process, improvise the communication encounter by adopting specific communication strategies. These strategies include: intimidation as a behavioural strategy to effect communication. Carers in this study also reported that effective communication requires planning to enable the creation of communication opportunities for service users to communicate. These include; choosing a suitable communication environment and allowing sufficient time for the service user to communicate at own pace.

These findings have strong implication for clinical practice

and in particular for health and social care professionals. The past decade witness a range of policies focused on involving people with learning disabilities in the provision and delivery of healthcare and effective communication is the medium for any meaningful involvement. The findings are further reflection that people with learning disabilities can communicate and express their needs. Service user made determined effort to ensuring that the communication is successful and clinicians need to be more mindful not to pre-empt their thought but to be more susceptible to the communication needs of people with learning disabilities.

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6/6