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COMMENTARY

Communication in stroke: the overlooked rehabilitation tool

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Abstract

People who have had a stroke and their families at every stage post-stroke state that they require more information. They wish to be informed about all aspects of their stroke and their care and be involved in decision-making. Several evidence-based reviews have found that information provision in stroke is inadequate and that future work should address the expressed needs of stroke survivors and families. Utilising research and personal experience as the spouse of a stroke survivor, this author makes a plea for better communication in stroke. The first steps to achieve this include the following. (i) Acknowledgement that stroke communication needs to be improved and that improved communication could affect outcomes not only for stroke survivors and their families but for professionals as well. (ii) The content of post-stroke communication needs to be delineated. Professionals have conflicting opinions on how to talk about uncertain recovery and a life post-stroke that includes disability. (iii) Proposing that stroke communication must support identity. Communication in stroke needs to be improved and communication should support identity.

Introduction

I come to this paper as the wife of a stroke survivor, the mother of two children, a founder of a website for families who are dealing with stroke, and a student of communication as the key to identity. After my husband lost the use of the right side of his body on 30 November 1997 and could not speak, he was taken by ambulance to hospital. In the emergency department, I was shown the CT scan and informed that it was not a haemorrhage that had caused the stroke symptoms. At that time, John was admitted into a general medical ward in the hospital under the care of an internal medicine specialist. Two days after the stroke, I brought our children in to see John for the first time. Just after we arrived the medical resident came into the room; 'The neurologist has just been here, we have done another CT scan, and he can talk to you now'. I was torn between my concern for John and for my children seeing their father for the first time, and the necessity to be informed by the professional with the most knowledge, about exactly what had happened to my husband, why, and what could be done. We walked into the hallway, where the neurologist did the entire consultation; with dinner trays being carried to and from rooms by nurses, families arriving to see their loved ones, nurses scurrying to finish their work towards the end of their shift, and numerous curious onlookers listening to the conversation about John's condition. The neurologist very quickly went over information on the brain damage from the CT scan, his prognosis, and his negative prognostications for rehabilitation. I was screaming inside, 'This is not professional communication!'. I found I was not alone in feeling that communication should be improved. Often, when caregivers or stroke survivors find fault with communication after a stroke, complaints are dismissed as 'doctor bashing' or 'disappointment with recovery achieved'. It is time to stop ignoring the evidence that professional communication needs to be improved, and look at the benefits of improved communication for professionals, stroke survivors and families. I have three goals in this paper:

i. Make the case for improved stroke communication. I believe that improved communication could affect outcomes not only for stroke survivors and their families but for professionals as well.
ii. The first step to improved communication is definition of the content of post-stroke communication. Professionals have conflicting opinions on how to talk about uncertain recovery and life, post-stroke, that includes disability.
iii. A proposal for communication that supports identity rather than concentrating on the physical disabilities.

Communication is key to stroke outcome

Stroke survivors and caregivers identify communication difficulties throughout the stroke care system and across all professions. Clark [1] and Pound *et al.* [2] found that patients felt that it was the role of doctors and hospitals to provide information, explanations, encouragement, and advice,

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but almost half believed that this need was not being met. Spouses in particular felt this [2]. Spouses think that information should be freely offered and resented needing to make specific requests for details. Wellwood *et al.* [3] stated that over 70% of carers had to ask for information. Rodgers *et al.* suggest '…despite widespread evidence of the need to improve information-giving for stroke patients and carers relatively few evaluations of the content and methods of delivery have been undertaken' [4]. As well, the evidence-based reviews of Forster *et al.* [5] and Teasell *et al.* [6] affirm that while formal information provision or educational interventions may be successful in improving patients' and caregivers' knowledge about stroke, this knowledge is not translating into better overall health or well-being for either patients or caregivers, nor did it alter outcomes in stroke. Researchers continue to focus on 'lack of information' as lack of specific technical medical information rather than unpacking this into communication of information and knowledge and how people use the messages to restructure life after stroke.

Effective professional medical communication has been shown to increase professional and patient satisfaction, reduce levels of anxiety, contribute to patients' sense of control, improve understanding of risks and benefits, help make definitive decisions about treatment courses, increase satisfaction with decisions, and increase adherence to treatment regimes [7–9]. Although the clinical value of good medical communication is unassailable, there have been ongoing debates about whether communication is an innate talent or a skill that could be taught. Mounting evidence shows that teaching and learning effective communication skills is an achievable goal but that 'To be effective you have to focus on specific and numerous skills, not just on some vague notion of improving communication in general' [8]. Kurtz delineates five necessary elements for improving communication:

i. Systematic delineation and definition of the skills to be learned.
ii. Observation of learners performing the skills (live or on videotape).
iii. Well-intentioned, detailed, descriptive feedback (preferably with videotape).
iv. Practice and rehearsal of skills.
v. Repetition (i.e. a helical, reiterative model rather than a once done model) [8].

The first step in achieving better communication in stroke is defining the skills to be learned, and especially what the content of the communication should be.

Content: what are we saying?

Professionals and stroke survivors are put into a predicament talking about recovery and life post-stroke. How do we talk about a life post-stroke that includes disability? Bendz [10] found that professionals communicate about bodily impairment, problems of reduced functions, and treatment of patient's disease, whereas stroke survivors portray themselves as individuals with a life in society that they wish to recapture. This dualism has prompted researchers to suggest that the goals of stroke survivors and their caregivers may differ from that of professionals [10–12]. Professionals debate whether their communication gives stroke survivors and families 'hope' and recovery after stroke *versus* creating over-optimistic expectations of 'recovery' and 'unrealistic expectations'. Does the language we use de-motivate patients by giving them bad news or is it patients' and caregivers' unwillingness to 'accept' the reality of stroke [4, 7]? Is life with disability unhealthy, unliveable, or less valuable? Is there a different way of communicating about stroke that would help everyone—professionals, stroke survivors, and their families—to move away from the dualism and rescript the post-stroke narrative along the entire stroke 'recovery' trajectory?

Professionals working with people who have had a stroke, stroke survivors, and caregivers all want to achieve the best possible recovery from stroke, but what 'recovery' from stroke means, how we communicate about recovery, and how we communicate about stroke disability and life after stroke are imprecise [13]. For example, John has aphasia as the result of his stroke. At first he could not speak at all, but with persistence we (John, our children, and I) feel he is able to communicate very well. We are very pleased with how John contributes to our family life. The neurologist, at a regular office visit a year after the stroke, asked, 'Has your speech always been this bad?'. From within the traditional medical model, health and well-being are often defined by professionals as what was pre-stroke. Any disability is defined as a deficit; pre-stroke life is superior; post-stroke life is seen as devastating and substandard.

In stroke, goals and outcomes are generally measured in terms of functional recovery, physical and task-oriented improvement. However, many people who are successful at achieving a full functional recovery on the Barthel Index and the Activities of Daily Living Scales still report poor quality of life, suffer from significant depression, avoid social activities, and have a negative sense of self [13–18]. Dowswell *et al.* delineate this, 'A major issue which emerges from this study is the need to review the meaning and experience of the term "adjustment to stroke" and the everyday terms "recover" and "recovery" [13].'

Identity is key to stroke outcome

Dr Robert Buckman defines bad news as 'any news that drastically and negatively alters the patient's view of her or his future [7]'. The cyclist Lance Armstrong's statement: 'I left my house on 2 October 1996, as one person and came home another' describes the impact of bad news on one's self-image [19]. In stroke care and rehabilitation, the focus is on the physical performance aspects with little attention being paid to the psychosocial aspects of stroke or what stroke does to identity [6, 14–16, 18, 20]. Kaufman and Becker [12] were first to talk about the profound identity assault stroke brought on what they call the 'taken for granted body' and the 'natural right sense of self'. It alters the stroke survivor's ability to perform previously valued social roles and is further complicated by the substantial effect on family dynamics [12]. Glass and Maddox [21],

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using the work of Lewin and Parkes, state that because stroke affects many domains at the same time, it affects the assumptive world and life-space of the stroke survivor. Identity, self-concept, and role capability are all challenged [21]. Life after stroke is about rebuilding, re-establishing, or recreating a coherent sense of self, and the roles that fit this new identity. Ellis-Hill and Horn explain this using a narrative approach.

> Their sense of self has been affected by stroke, applying a life narrative approach it can be concluded that their sense of coherence with their past had been undermined and their future had become unpredictable. When individuals cannot create a clear sense of future self, they experience anxiety and become unsure how to act. In this situation, individuals who have had a stroke may settle for a restricted future self with limited physical and social activity, because this is what they expect of a life with disability [15].

Our identity, perception of self is interactively and progressively realised through the inclusions, exclusions, and negotiations with others. 'The self as humans know it, is a distinctly interactive, interpersonal concept. Communication with others is an indispensable vehicle for self-development. The self emerges through being in the world, the culture of the times, and the company that is kept' [22]. After a stroke, development of an attitude of 'mastery despite deficit' [21] is facilitated (or hindered) by: the social environment, the information and communication transactions that the stroke survivor and the family have with each other, and communication with other people in the environment. What happens in those transactions, how positive or negative they are, will promote or hinder the survivor's belief in his or her ability to solve problems, control his or her situation, and affect his or her sense of self-efficacy.

Bendz's [10] audit of conversations in hospital found that professionals and stroke survivors have differing perspectives about identity; stroke survivors portray themselves as individuals with a position in society that they are trying to recapture, whereas the medical care personnel categorise them by their deficits. This was our experience as well. In rehabilitation, John would talk about what he might be able to do at work after he was discharged. The professional answer was that deficits, speech and 'processing speed' would prevent John from working. Professionals want to ensure that people 'accept their situation' and are realistic about their life with disability. However as Kirkevold [18] suggests, and our experience indicates, re-establishing identity after stroke evolves with time and messages about disabilities may not contribute positively to the process. Teasell *et al.* [6] would concur with this, 'the transition of the stroke experience calls for the need to re-establish functional independence while incorporating residual deficits into a new personal identity'.

Caregiver roles and identity also change but this is often disregarded because the person with the stroke is the patient. The role change from spouse to caregiver, taking on the tasks done by two people pre-stroke, and perhaps dealing with significant behavioural and cognitive changes of your life partner may be as daunting an identity transformation as that faced by the person who has had the stroke. Lambert and colleagues summarise, 'our identity is the prime mover in health cognitions and behaviours, and because identity is itself the product of communicative interactions, communication must be at the very core of what it means to be healthy' [23].

Our goal in stroke communication, from the outset, should be to support individuals and families in creating a positive post-stroke identity. The four key factors that have been correlated with the improved outcome in stroke—family support, ability to solve problems, social support, and perceived control—are also associated with improving self-image and identity [20, 21, 24–27]. We need to look at how professional communication shares control with stroke survivors and families, helps them to find their own solutions to problems, and encourages them to access social support.

Conclusion

Redefining identity after stroke, exiting the sick role, and regaining health depend upon all communication interactions with stroke survivors, families, and professionals. We have assumed that it is the science of medical treatments that produces outcomes and have overlooked the role of the art of communication. Professionals cannot redefine identity for stroke survivors and their families after stroke. Stroke survivors and families must do that work on their own, with the collaboration of professionals. 'The limits of medicine assure that patients cannot always be cured. These are precisely the times that professionalism most acutely calls the physician to provide hope and healing for the patient' [28]. That hope and healing should be in the form of more effective communication to help reframe the narratives about a life with residual stroke disability.

I believe even more today that effective communication can be as powerful a tool in stroke recovery as any technical medical intervention. Rebuilding a positive post-stroke identity is the key to a more meaningful and satisfying life, but research is needed to provide evidence. Relatively little is known about the content and structure of informal communication transactions between stroke survivor, family and healthcare professionals, and how they accommodate (or resist) realignment of identity after stroke. How does professional communication influence outcome? Stroke survivors and families complain about the negative discourses regarding possibilities for life after stroke and recovery and the hopelessness that this creates, whereas professionals are concerned with ensuring that stroke survivors are given 'realistic expectations' of recovery. How do these different discourses affect outcomes? Research is also needed on how stroke survivors and families utilise communication. How do they make use of communication to restructure their lives? What information do they use and what is ignored?

Stroke is the leading cause of adult disability and each year an additional 50,000 Canadians have to deal with stroke. While we are looking for a magic bullet that will prevent stroke or erase the brain damage in the event of stroke, it is

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paramount that we use every tool we have available to improve the quality of life for people who have had a stroke. The possibilities of improved outcomes from better communication can be a significant prize for everyone involved in stroke treatment, professionals, stroke survivors and families! Dr Robert Buckman leaves us with these words: '. . . the skill and effort that we put into our clinical communication does make an indelible impression on our patients, their families, and their friends. If we do it badly, they may never forgive us; if we do it well they may never forget us' [29].

Key points

- Stroke communication needs to be improved and that improved communication could affect outcomes not only for stroke survivors and their families, but for professionals as well.
- The content of post-stroke communication needs to be delineated. Professionals have conflicting opinions on how to talk about uncertain recovery and a life post-stroke that includes disability.
- Stroke communication must support identity.

References

1. Clark MS. Patient and spouse perceptions of stroke and its rehabilitation. Int J Rehabil Res 2000; 23: 19–29.
2. Pound P, Gompertz P, Ebrahim S. Patients' satisfaction with stroke services. Clin Rehabil 1994; 8: 7–17.
3. Wellwood I, Dennis M, Warlow C. Patients' and carers' satisfaction with acute stroke management. Age Ageing 1995; 24: 519–24.
4. Rodgers H, Bond S, Curless R. Inadequacies in the provision of information to stroke patients and their families. Age Ageing 2001; 30: 129–33.
5. Forster A, Smith J, Young J, Knapp P, House A, Wright J. Information provision for stroke patients and their caregivers (Cochrane review). The Cochrane Library, Issue 4. Oxford: Update Software, 2002.
6. Teasell R, Doherty T, Speechley M, Foley N, Bhogal SK. Evidence Based Review of Stroke Rehabilitation. London, Ontario: Ministry of Health and Long Term Care & Heart and Stroke Foundation of Ontario, 2002.
7. Buckman R. Breaking bad news: why is it so difficult? Br Med J 1984; 288: 1597–9.
8. Kurtz SM. Doctor-patient communication: principles and practices. Can J Neurol Sci 2002; 29 (Suppl 2): S23–9.
9. Wiles R, Pain H, Buckland S, McLellan L. Providing appropriate information to patients and carers following a stroke. J Adv Nurs 1998; 28: 794–801.
10. Bendz M. Rules of relevance after a stroke. Soc Sci Med 2000; 51: 713–23.
11. Doolittle ND. The experience of recovery following lacunar stroke. Rehabil Nurs 1992; 17: 122–25.
12. Kaufman SR, Becker G. Content and boundaries of medicine in long term care: physicians talk about stroke. Gerontologist 1991; 31: 238–45.
13. Dowswell G, Lawler J, Dowswell T, Young J, Forster A, Hearn J. Investigating recovery from stroke: a qualitative study. J Clin Nurs 2000; 9: 507–15.
14. Burton CR. Living with stroke: a phenomenological study. J Adv Nurs 2000; 32: 301–9.
15. Ellis-Hill CS, Horn S. Change in identity and self-concept: a new theoretical approach to recovery following a stroke. Clin Rehabil 2000; 14: 279–87.
16. Hochstenbach J, Donders R, Mulder T, Van Limbeek J, Schoonderwaldt H. Long-term outcome after stroke: a disability-orientated approach. Int J Rehabil Res 1996; 19: 189–200.
17. King RB. Quality of life after stroke. Stroke 1996; 27: 1467–72.
18. Kirkevold M. The unfolding illness trajectory of stroke. Disabil Rehabil 2002; 24: 887–98.
19. Armstrong L. It's Not About the Bike: My Journey Back to Life. New York: Putnam, 2000.
20. Lewis SC, Dennis MS, O'Rourke SJ, Sharpe M. Negative attitudes among short-term stroke survivors predict worse long-term survival. Stroke 2001; 32: 1640–45.
21. Glass TA, Maddox GL. The quality and quantity of social support: Stroke recovery as psychosocial transition. Soc Sci Med 1992; 34: 1249–61.
22. Norton R, Brenders D. Communication and Consequences: Laws of Interactions. Mahwah, NJ: Lawrence Erlbaum Associates, 1996.
23. Lambert BL, Street RL, Cegala DJ, Smith DH, Kurtz S, Schofield T. Provider–patient communication, patient-centered care and the mangle of practice. Health Commun 1997; 9: 27–43.
24. Glass TA, Dym B, Greenberg S, Rintell D, Roesch C, Berkman LF. Psychosocial intervention in stroke: Families in Recovery from Stroke Trial (FIRST). Am J Orthopsychiatry 2000; 70: 169–81.
25. Grant JS, Elliott TR, Weaver M, Bartolucci AA, Giger JN. Telephone intervention with family caregivers of stroke survivors after rehabilitation. Stroke 2002; 33: 2060–65.
26. Johnston M, Gilbert P, Partridge C, Collins J. Perceived control, coping, and recovery from disability following stroke. Psychol Health 1999; 14: 181–92.
27. Purkey W. An overview of self-concept theory for counselors. Ann Arbor, MI: ERIC Clearinghouse on Counseling and Personnel Services, 1988 (An ERIC/CAPS Digest: ED304630).
28. Vandelieft GK. Breaking bad news. Am Fam Physician 2001; 64: 1975–8.
29. Buckman R. Communications and emotions. Br Med J 2002; 325: 67.

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