Title: Post-stroke communication impairments: unmet needs of patients and carers identified through an online stroke community.

Problem: One in three stroke survivors with communication impairments have unmet needs, which are currently poorly defined. Better understanding of these needs can inform more effective care with provision of appropriate services and support. The aim of this study was to explore whether and how practical unmet needs of stroke survivors with communication impairments were discussed in an online stroke community, and whether participation was a way of addressing demand.

Approach: The TalkStroke archives (2004-2011) were explored with different keywords linked to communication impairments. Relevant posts were best identified using the keywords speech and language and thematically analysed. If selected posts were replies, the original posts in the threads were also coded.

Themes surrounding requests of support of stroke survivors with communication impairments were identified. The contribution of engagement in the online community to address queries was explored using the Social Support Behaviour Code.

Findings: 185 relevant posts were identified from 102 users: 49 male, 35 female, 18 unstated; 15 stroke survivors, 87 survivors talked about by third party; mean age at stroke 58.0 years, 0-2+ years after stroke. Posts at the start of threads were written by family members of stroke survivors with communication impairments while the patients were still in acute stroke settings. These posts followed a pattern: an introductory narrative, a report of the problems experienced with communication; measures implemented to tackle communication issues followed by a statement of outstanding unmet needs, leading to requests for advice from the personal experiences of other users. Replying users were most likely to be experienced survivors who suffered from a stroke several years earlier, with superusers in the online community (users who engage with the online community most frequently) playing a crucial role.

Through participation, users mostly received informational support in the form of practical strategies, such as the use of lightwriters, alphabet and memory boards. Emotional support was provided mostly through words of encouragement and comments or stories that showed understanding and empathy. Network support included the provision of contact numbers and web addresses for relevant NHS or charity services and reassurance that community members would be available to help through the online community where possible.

Implications: Practical unmet needs of stroke survivors with communication impairments and their families were discussed in an online stroke community. Participation was mainly triggered by problems with communications experienced by patients while in acute stroke setting. The online community created a space for stroke survivors to share their extensive first-hand experience with managing post-stroke communication impairments. The dataset used in this study is relatively old and results may not represent current practice.

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