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Active citizenship and acquired neurological communication difficulty

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Abstract

Purpose: People with communication impairments may face barriers to civic participation, with resulting marginalisation of individuals who wish to be actively involved. The investigation aimed to explore the experience of civically engaged adults with acquired neurological communication difficulties.

Method: Six people with acquired neurological communication difficulties were interviewed. Discussion included the definition of active citizenship, their civic involvement, motivations, related barriers and facilitators. Qualitative analysis was undertaken, with data categorised, coded and examined for recurring themes.

Results: All participants were active in disability-related organisations and four undertook wider civic roles. Motivations included activity being outwith the home and wanting to effect change for themselves and the populations they represented. Disability group meetings were more positive experiences than broader community activities, which were associated with fatigue and frustration, commonly resulting from communication difficulties and unmet support needs. All participants identified a need for professional and public educational about disability and communication and made recommendations on content, methods and priority groups.

Conclusions: For these participants civic engagement had positive and negative dimensions. Speech and language therapists should promote reduction of the barriers that impede the active citizenship rights of people with communication support needs. Civic participation may be a relevant measure of outcome in communication impaired populations.

Description of participation in life situations of people who have communication difficulties is aided by the international Classification of Functioning, Disability and Health (ICF) framework [1]. Within this framework disability is viewed in terms of interaction between the individual's health diagnosis and relevant personal and environmental factors. Research has shown that people with aphasia have reduced participation in leisure and domestic activities, employment, and education, but participation in civic life has been largely ignored [2]. Similarly for other communication impaired groups, such as dysarthria and dementia, consideration of 'personhood' has generally not extended to 'citizenship', a concept which encompasses connection to wider society, rights and responsibilities, and the capability for exerting power and influence [3].

Within this paper, civic and community are treated as similar concepts, consistent with the definition of civic as 'connected with the duties and obligations of belonging to a community' [4]. Civic participation encompasses varied formal and informal community-based and political pursuits, normally unpaid. Typically there is involvement in structured organisations and groups, whose activities generally include attending meetings, volunteering, and fundraising [5]. Opportunities are provided for engaging with others, voicing concerns and contributing to improvement in life conditions and experience, which may benefit the individual and society [6]. Such active citizenship is thought to promote personal development and learning and for many people is a component of well-being and life satisfaction [7].

Disability legislation in the UK provides the right to equal access. Nevertheless for people who have communication difficulties, opportunities for full civic participation may be affected by negative environmental factors and absence of communication facilitators. Adults with communication impairments play an active role in campaigning to raise awareness of difficulties they may face, and for improvement in services, attitudes and communication accessibility. A recent UK example is the two year media campaign run by the Aphasia Alliance, a coalition of 10 organisations working in the

field of aphasia, including Speakability and the Stroke Association. In the Scottish context and encompassing a broader field than aphasia , Communication Forum Scotland (CFS([8] is an informal alliance of organisations representing people with communication support needs (CSN). People who have CSN are those 'who experience difficulties expressing themselves and understanding others, such that it affects everyday functioning'([9](P1). CFS aims to highlight the diversity of such needs and promote ways of meeting them. The online resource 'Talk for Scotland: a practical toolkit for engaging with people with communication support needs' [8] exemplifies CFS's activity. Through its Civic Participation Network (CPN) project, CFS strives to remove barriers for those with CSN in local, regional and national decision making activities.

The investigation aimed to explore the experience of civically engaged adults who have CSN resulting from acquired neurological lesions, with reference to motivations, barriers, and changes which might facilitate the more effective civic participation of people with CSN.

Method

The topic of civic participation and the aims of the investigation were discussed at a CPN meeting. The group discussion informed issues to be explored via individual interview. Six CPN members with acquired neurological communication difficulties consented to be interviewed by MC and quoted in publication. The interviewer was a clinically experienced speech and language therapy student who was undertaking a university internship. She was present at the CPN meeting at which the investigation was discussed, but had no other prior contact with the participants. The informed consent process used accessible language and format. There were three males and three females, age range 54 – 78, with varied neurological and communication diagnoses and symptom duration ranging from three to 22 years (see table 1).   None was in paid employment. The interviews

comprised eight short questions, without complex grammar, exploring the definition of an active citizen, the individual's civic involvement, motivations for this, barriers to and facilitators of civic participation. Participants received the questions in written form in advance and during the interview these were available and referred to, with explanation and expansion when either requested or judged appropriate by the interviewer. The interview style was conversational with speech clear and at an appropriate pace. All participants were able to respond verbally. Where meaning was unclear, clarification and verification were pursued. The interviews were conducted in the participants' homes, and lasted from 25 to 75 minutes.

The participants presented difficulties with language, communication and motor speech which variously impacted on the clarity, efficiency and effectiveness of their own spoken and written communication and their understanding of the spoken and written communication of others. Therapy outcome measures (TOM) [10] ratings were assigned to provide summary information of impairment, activity, participation and wellbeing/distress, using the scale appropriate to each participant: 3, 6, 13. Ratings were made independently by CM, MC and an independent researcher, MM, based on the interview video-recordings and transcripts and the information conveyed therein. There was agreement between at least two of the three raters for all 24 scores and these agreed scores are given in table 1.

[table 1 about here]

MC transcribed the response data orthographically from the videorecordings. CM checked the transcripts against the recordings and made very few amendments, relating to omitted words or words not intelligible to the transcriber, none of which affected information content.

Data analysis was carried out by CM. The first step was immersion in and becoming familiar with the data, through viewing the recordings, reading and re-reading both the entire transcripts and their sections. Next, content which was unrelated to civic participation, for example discussion of shopping and banking experiences, was discounted. The analysis procedure outlined by Granheim and Lundamn (2004) [11], and used previously with aphasic data [12], was applied to the remaining text. Meaning units were condensed and coded. Codes were examined for similarities and differences, providing categories which were then examined for themes. MM reviewed all recordings and transcripts, and examined the data tables with reference to codes and categories, checking for omissions, and appropriateness of groupings into categories and themes. The framework for data handling was deemed to be valid and comprehensive and the content assigned to the themes agreed. No significant omissions or over-interpretations were noted in the data tables or analysis reporting.

Results

The interview data are reported in relation to four themes 1) participants' civic involvement; 2) motivations and perceived benefits; 3) negative experiences, obstacles and facilitators; 4) education. Illustrative quotations are included in insert boxes.

Civic involvement: Participants largely understood active citizenship in terms of community involvement. Two offered broader definitions, including dealing with statutory authorities such as health and education, and participation at national versus local level. Both stressed that 'active' denoted a high level of commitment or leadership, which described their roles. All participants were members of local branches of voluntary organisations relevant to their neurological disease (e.g. Parkinson's Disease Society) or communication difficulty (e.g. Speakability), and two had leading

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committee roles within these. In addition to attending standard meetings, which were largely social and informative, all participants were active in these organisations. They gave educational talks to health professionals and students, politicians and other groups, took part in media interviews, and in fundraising, which included production of a joke book and application to wealthier charities and Government for specific project funding. All participants were active in the CPN project. For four participants, voluntary organisation membership had led directly to a patient representative role at national level or in health forums with a broad remit, such as hospital department relocation and optimising hospital meal nutritional content. Two of these participants, one of whom had the lowest TOM impairment rating of the group, undertook further civic activities which were nor related to their illness or disability: charity shop volunteering and co-ordinating information for a housing complex newsletter and both also attended community classes.

Motivations and benefits: Civic involvement was a new activity for three of the group, all of whom described themselves as previously too busy for civic engagement. The other three participants had always been civically active, but with a different focus from their current activities.

Participants were motivated by a desire for activity which did not centre on the home (a-b) and by wanting to effect change for themselves and the populations they represented, which they saw as disadvantaged or excluded from society (c-e). They referred to individual personal benefits arising from their participation, including enjoyment of the role and the challenge, having fun, increasing confidence, and helping to deal with anger and frustration associated with their current situation. Being with people with whom they shared the disability experience and having opportunities to communicate with others with similar difficulties was important. One individual communicated more in this situation than with family and friends, with whom communication was reduced through self-consciousness (f-g). Some participants referred to the process of becoming involved as having

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been a difficult one, which had taken some time and had been influenced by others, such as nurses and therapists (h). One participant who now was in worldwide email contact with members of similar disability groups referred to having needed 'to start a new journey'.

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a) 'You know there is a house, there is your family, there's your garden but you know there is a little bit more' (P1)

b) 'I felt like a zombie just and I went 'what am I going, what am I going to do here? Am I going to life like this? Am I going to sit like here?' (P5)

c) 'I became angry at the conditions at that time and felt I can do something here about this' (P6)

d) 'Our members are the most disadvantaged of all……and because it helps me, you see people who help others help themselves' (P2)

e) 'Really want to change for people with aphasic. That was the worst of my life. I just feel I want to awareness people' (P5)

f) 'A great help and support to be with people suffering the same way' (P3)

g) 'You can understand with aphasic and say 'oh I've had this' or 'you felt this' and it made a big, big difference………..you feel comfortable because if you talk rubbish you go 'oh I'm talking rubbish, sorry'. We just go on whereas you feel dead stupid with a normal' (P5)

h) 'And I said I'm not ready yet and she says well you're only either going to sit there and do nothing or your going to do something' (P5)

Negative experiences, obstacles and facilitators: Social activities and meetings within their own disability groups were positive experiences, though two participants referred to the emotional strain

of being closely involved with people who had serious problems, and in the event of members dying (i). In contrast to these affirmative and constructive encounters, all participants spoke about negative aspects of their broader community participation. One participant referred to the stigma of disability, arrogance and absence of respect from some professionals. Lack of results from their efforts and of positive feedback was depressing and frustrating. Four people referred to tiredness, fatigue and reduction in personal time (j-k). One individual who was very aware that frequent meeting commitments had resulted in seeing less of friends had reached a decision to reduce the amount of committee work. Another participant conveyed feeling burdened by the extent of involvement which arose from the limited number of people willing or able to undertake an active role. Physical and related travel difficulties, which were frequently overlooked by those organising meetings and events, added to the negative experience (l). Taxi transport was appreciated and facilitated involvement in situations where attendance was otherwise more difficult. One participant offered a series of practical points about meeting organisation which would aid concentration and participation: breaks should be scheduled, the room quiet, with comfortable seating and good ventilation.

Problems directly associated with communication were dominant in some instances. Individuals referred to 'getting in a state' over difficulty with words, being self-conscious about lack of fluency, and how tiring it is to speak at meetings. One participant required to work away from the public in a charity shop because people attributed speech difficulty to inebriation. A participant, who appeared to be the only member with communication difficulties in a health forum, was upset that personal initiatives for communication support, such as asking for group members to wear name badges, were not well received, and believed that there were both gender and disability discrimination issues (m).

The presentation of both spoken and written language led to difficulties in civic participation. People's speaking rate was perceived as usually too fast. Understanding of speech was thought to be aided by speaker repetitions, and slower, clearer speech. One member referred to the special difficulties of obtaining details about meetings from answer-machine messages, where information was given only once and was not slow and clear. Accompanying speech with written material, and in some situations gestures and visual clues was helpful, though one participant thought that pictures may be perceived as patronising. Regarding their own spoken contributions there was a general sense of being rushed (n) and a need for more time for response. One participant referred to being 'spoken over', not being listened to closely enough, and the added difficulties of background noise. This individual advocated establishing participation 'ground rules', including listening to each other, at initial meetings (o). Taking notes at meetings was difficult and further affected by low lighting. The font size of printed material was invariably too small and colours, font and background styles could be additional obstacles. One participant referred to the 2007 Scottish Parliament Elections voting experience, in which local and parliamentary ballots were held together, using different recording systems. An unprecedented number of ballot papers were rejected as invalid. Analysis of this situation, including by disability groups [13] concluded that contributory factors included the different voting systems, unclear presentation, limited instructions and absence of visual prompts.

Although the participants provided many suggestions for actions by others to remove obstacles to participation, they thought people with CSN had responsibility for initiating action to facilitate their participation. Amongst examples of strategies adopted were asking someone else to take your notes at meetings; using a script with pause points inserted; requesting slowed repetition; frequent 'rehearsing'; visualising the written form of a spoken word; 'really listening'; keeping a diary. Three of the group advocated being willing to explain difficulties, orally, or by providing a card or advice booklet, and asking for help, and one other obtained help with scripts for talks (p).

Hewitt and Byng (2003)[14] referred to participation being vital for many people but also to the mistaken notion that 'all people with disabilities want to participate and do things' (P53). In discussing the roles they undertook, the group members recognised that active civic involvement was not appropriate for everyone with communication disability. One participant thought that having limited education and poor communication would reduce credibility in certain situations. Lack of confidence, fearfulness and stress were believed by four of the group to prevent people from civic participation. They thought this anxiety may be related to communication, such as being worried about 'poor speech', but was also present at a more general level. One participant thought if people with difficult, dominating personalities were encountered this was a deterrent. Another member referred to difficulty of coping with 'public exposure'. Three of the group spoke about there being a stage of readiness for participation which an individual may not have reached and which may be related to self-image and willingness to 'turn your back on the whole thing' (q).

i) 'I find for myself personally with it is being so close to it and so close to it all the time, its very hard emotionally and energy, you're always reminded of your own situation. You know it's always easier to go away and pretend this isn't happening' (P6)

j) 'Sometimes you know you know you feel pretty awful. I don't want to go there and I want two days by myself . Sometimes, sometimes it can get be very very tired and sometimes you can get depressed about it - like here we are again I've tried this' (P1)

k)' It's very difficult to carry on with community and citizen work as it were and still keep up any quality of life for myself '(P3)

l) 'And they think everybody just lives around the corner, yes it's all five minutes, we're all going about with chauffeur driven cars' (P6)

m) 'In fact I was going to resign because I wasn't happy and I think this is quite interesting because the men don't like this thing, maybe I'm being a feminist. I do think sometimes people go 'uh there's the woman that has the brain problem' but sometimes I think they have the brain problem and not me ' (P1)

n) 'People don't have enough time to listen' (P4)

o) 'And you give people time to be heard and also give them time to get out what they want to say, and at the end of the day everybody's stuff have been covered when they are participating in the meeting.' (P4).

p) 'The only thing one can do is em just to be open about the problem' (P3)

q) 'I'm not doing that. That's not my life. I was this, that and the other. I can realise why people stay in their ……..what do you call it?' (interviewer suggested 'comfort zone'). 'Yeah' (P1)

Education: In addition to providing general advice on the removal of current barriers to civic participation, all participants referred to a need for education about disability and communication difficulties and forwarded opinions and recommendations relating to their experiences. They thought education should encompass the variety and severity range of disabilities which affect people, day to day variation in functioning, the seriousness of having a communication difficulty, the breadth of communication difficulty, its implications, and how all areas of life are affected (v). Three participants referred to public ignorance or 'lack of imagination', and another to the need for compassion. One participant was especially concerned with working towards removal of the stigma of disability, and fear of contact with disability, including within families.

Educational methods employed by individuals included information and advice presentations using powerpoint; telling their own stories; production of informative literature and a DVD; questioning to facilitate audience discussion; involving audiences in role play and highlighting poor practice; envisaging being in an everyday situation, such as travelling by bus, when unable to speak. One participant stressed that the education process had to be approached sensitively (w) and another spoke of the benefits of humour.

Aside from generally raising society's awareness of disability, the main groups identified as priorities for education and communication training were 1) people employed or training in health or social care, including care assistants, speech and language therapists, and medical doctors, especially general practitioners, and 2) families of those with disabilities. Individual participants variously thought education to be important for politicians given their policy influencing role; young children, who may be more receptive than older children; employees in libraries, banking, including tele-banking and prisons. One participant identified a special education need for hearing impaired populations, cultures for whom disability is conventionally viewed as shameful, or where knowledge about disability is limited. One participant saw researchers seeking to recruit at disability group meetings as a priority group, often in need of general education about speaking to groups, particularly where older people were present (x). Two participants referred to the increasing need for education about disability which will arise from society's aging profile.

v) 'it's not just one thing. It's the whole day to day, like what I've said the shops, banks, even someone your door and you try to speak for like a window people and your standing and can't get your number, your words, and you feel stupid' (P5)

w) 'so I think they need a lot of work, nicely, nicely' (P1)

x) 'talking to a group, even if it's a small group, is not the same as chatting away to your friends in a pub or something, and they have to of course basically the first basic thing is they have to be able to explain what their research is about clearly and secondly got to project their voice. If there are questions from em a member of the group they tend to start having a dialogue with that particular person which the rest of the group can't' hear………. may not have even heard the question' (P3)

Discussion

Understanding, sensitivity to others and a sense of oneself that enables listening to and learning from others are necessary for active civic engagement [15]. Extent of civic participation is affected by opportunity, personality, time and resources, and varies across the lifecycle. Disabled people are less likely to be involved in formal volunteering than are people without a disability [16]. Active citizenship emerges at a point of personal readiness which Erikson [17] refers to as the generativity stage as distinct from the stagnation or self-absorption stage of development. This notion of readiness was clear in the descriptions of circumstances and influences leading up to participants becoming active citizens and also the inward-looking, self-focus which they thought hindered others in similar situations. In the face of acquired disability, including where communication is affected, reconstruction of identity may be necessary and this process may be aided by civic participation. For all members of the group 'coming out' as a communicatively disabled person had been a purposeful decision and the study provided rich data on their experiences, both positive and negative.

A major component of how the participants viewed and realised active citizenship was through involvement in voluntary organisations related to their disabilities. Jones and Gasiorski [7] noted that such 'grassroots activism', whereby people promote a cause with which they have strong

identification is 'often the civic participation pathway for marginalized groups' (P661). This type of participation features little in general discussions of civic activity and is under-researched.

Participants were stimulated to civic engagement and continued to be motivated by personal and altruistic dimensions. At a personal level much of the initial motivation was related to opportunities for activity and socialisation outside the home, an ongoing benefit of which was the support of interacting and communicating with people who shared their experience. Three participants used vocabulary such as 'fun', 'enjoy' and 'laugh' in describing the personal benefits. Altruistic motivation, in the sense of wishing to effect change for others , especially the groups which the participants represented, such as aphasia, dementia, stroke, tended to emerge over time. All participants were committed to their causes, though there were significant negative dimensions to maintaining an active civic role. Carrying out education and training were main components of their citizenship. Following these demanding activities at which stigma, lack of public knowledge and concern were often encountered, feelings of depression, frustration, and disappointment were common. Communication and physical difficulties, which were frequently not accommodated, involved considerable effort in being understood, in understanding others, in accessing locations of meetings and even in partaking of available refreshments. Personal time was eroded and there was much reference to tiredness, energy depletion and emotional strain. Individuals related wanting to do less, identifying a future need to reduce activities and having considered discontinuing their role. Nevertheless all continued to be active citizens for whom education about both disabilities and communication was of the utmost importance. This concern is consistent with Law et al's observations [9] that awareness and understanding of CSN is limited amongst both professionals and the general public. The variation in who participants thought were priorities for education somewhat reflected their individual experience and situation, for example family members, researchers, health and care staff.

Where participants undertook an educational role or extended their civic involvement beyond their disability groups, as for example patient representatives on committees, they encountered barriers to communication access and full participation, even where communication difficulty was mild. The major barriers identified were those well recognised, such as the speed of speech being too fast, background noise, not being given enough time to process or contribute and print being too small and otherwise not optimally presented. Such obstacles were described by the participants with dysarthria as well as by those whose language was impaired, highlighting that the understanding of spoken and written language may be affected by many sensory and cognitive decrements, especially in older age, which are not necessarily related to the neurological communication disorder.

Committee participation almost always includes working with printed information, though alternative recorded presentation should be made available. The experience of the group, and their suggestions as to changes which would facilitate accessibility of written material, accorded with the substantial body of research and recommendations regarding language, organisation, layout and typography which aid understanding [18]. Opinion was divided on the addition of illustrations. Simplified written material must not be patronising or childish.

All participants in the study were several years from onset of communication difficulty. They had been civically active for some time and had developed personal coping strategies, which included openness about difficulties and actively seeking help with communication. Two participants with aphasia carried a card or booklet explaining their condition and methods of supporting their communication, a strategy commonly suggested by service industry workers to facilitate community participation [19]. However one participant thought that this simple tool was under-used and not always offered to people with aphasia. Participants had mixed experiences of peoples' willingness to

accommodate their communication styles. One individual encountered much negativity and felt

unwelcome when requesting supportive strategies to facilitate participation in a health committee.

People with CSN should be active and not token members of committees. Their contributions should

be valued by others and not only by themselves [20]. They can advise on the conditions and support

which make this possible. Participants in the study forwarded experience-based practical

suggestions about transport to and the timing and general running of meetings, and about

establishing ground-rules to facilitate equal participation, which all meeting organisers should note.

Conclusions and clinical implications

The participant sample for this investigation was one of opportunity and is both too small and

diverse in its composition for generalisation. However because such case reports are recognised as

an important source of information on social outcome their dissemination is encouraged [21].

Further research in civic participation is justified, involving many more representatives of these and

other CSN groups, to allow examination of commonalities of experience and their guidance, as the

people best equipped to provide it.

Disability can bring with it social isolation and exclusion from participation in many areas of life [20].

Active citizenship may be a component of growth and change for people who have communication

difficulty. For all six participants TOM [9] wellbeing ratings were higher than impairment ratings,

indicative of acceptance of limitations, to which active citizenship may be a contributory factor.

There is a need for development of relevant measures of participation satisfaction and longitudinal

study which takes account of both the forms of engagement and amounts of time devoted to civic

activities. Speech and language therapists (SLTs) who are committed to extending their scope of

practice might show strong leadership in identification and working towards removal of barriers that

impede rights of people with CSN to participate actively in the community [19]. This requires that each person's situation is assessed individually in relation to barriers and facilitators [12].

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The investigation provided some insights into the civic activities of a small group of individuals. The potential avenues of civic involvement for people with CSN must not be seen to be restricted to the examples forwarded by this group. People who have CSN should be enabled to play an active role in political, religious, neighbourhood, sporting and social organisations. Similarly research, in all fields, should take account of CSN. Every community involves people who will be excluded from research participation if their CSN needs are not met. Rather than such individuals being 'hard to reach', lack of participation might be attributable to communication barriers and absence of facilitators.

The importance of documenting actual social participation is well recognised 'for capturing meaningful life changes' [22, P 299]. Such outcome measures should include the neglected field of civic engagement.

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Table 1

Participant information

Participant	Gender	Neurological and communication diagnoses	Impairment*	Activity*	Participation*	Wellbeing/ Distress*
P1	F	Stroke and aphasia	4.0	4.0	4.0	5.0
P2	M	Stroke and aphasia	4.5	4.5	4.5	5.0
P3	F	Parkinson's disease and dysarthria	4.0	4.0	4.0	5.0
P4	M	Stroke and dysarthria	2.5	3.5	4.0	4.5
P5	F	Stroke and aphasia	3.0	3.0	3.0	4.0
P6	M	Dementia	4.0	4.5	4.5	4.5

For ethical reasons biographical information has been minimised

*Therapy outcome measures ratings [10]: 0-5 scale

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