Physical environments and community reintegration post stroke: qualitative insights from stroke clubs

Katherine Brookfield & Gillian Mead

To cite this article: Katherine Brookfield & Gillian Mead (2016) Physical environments and community reintegration post stroke: qualitative insights from stroke clubs, Disability & Society, 31:8, 1013-1029, DOI: 10.1080/09687599.2016.1223606

To link to this article: http://dx.doi.org/10.1080/09687599.2016.1223606

© 2016 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group

Published online: 19 Sep 2016.
Physical environments and community reintegration post stroke: qualitative insights from stroke clubs

Katherine Brookfield\textsuperscript{a} and Gillian Mead\textsuperscript{b}

\textsuperscript{a}Edinburgh College of Art, University of Edinburgh, Edinburgh, UK; \textsuperscript{b}Geriatric Medicine, University of Edinburgh, Edinburgh, UK

\section*{Abstract}
This study investigated the environment’s role in community reintegration amongst persons with experience of stroke. Focus group discussions with 29 individuals recruited from community stroke clubs in Scotland revealed that stroke influenced a person’s perceptions, experience, use and enjoyment of the environment. Multiple specific (e.g. theatres, cafes) and more general (out-of-the-home) environments appeared capable of supporting community reintegration, providing settings in which individuals were able and willing to interact with others and participate in various functional, social and recreational activities. The article reflects on the study’s implications for policy and practice.

\section*{Points of interest}
• Community reintegration post stroke may be supported by multiple specific (e.g. theatres, parks, the home) and more general (out-of-the-home) environments.
• These can provide settings in which individuals are motivated to interact with others and participate in various functional, social and recreational activities.
• Stroke can have a profound impact on an individual’s perceptions, experience, use and enjoyment of the environment.
• Peer support is valued by, and may bring important benefits to, stroke survivors.

\section*{Introduction}
There are over 1.2 million stroke survivors in the United Kingdom whilst every year some 152,000 strokes occur, equivalent to one every 3 minutes 27 seconds (Stroke Association 2016). The prevalence of stroke increased by 12.5\% between 1999 and 2008, whilst the incidence of stroke fell by approximately 30\% (Lee, Shafe, and Cowie 2011). Improved drug treatment in primary care is likely to be a major contributor to the latter (Lee, Shafe, and Cowie 2011, 1). Our ageing population (Mayo et al. 2002), with age being the single most
important risk factor for stroke (Stroke Association 2016), combined with developments in acute stroke management and rehabilitation, leading to reduced stroke mortality (Lee, Shafe, and Cowie 2011), mean that an increasing number of people with stroke are now returning to the community (Wood, Connelly, and Maly 2010).

In the context of stroke, community reintegration can be defined as a person’s return to everyday functional activities, instrumental activities of daily living, recreational and social activities, and interactions with family members and others (Pang, Eng, and Miller 2007). It is, therefore, a relatively broad concept concerned with participation in various life domains. We focus here on community reintegration because evidence suggests it captures processes which are important to stroke survivors (although no judgement is passed on whether or why these processes should be considered important) (Bergström et al. 2015; Wood, Connelly, and Maly 2010). That poor community reintegration has been associated with depression, social isolation, a poor quality of life (Wood, Connelly, and Maly 2010) and reduced life satisfaction (Astrom, Asplund, and Astrom 1992) underlines its importance.

Community reintegration is, of course, neither an unproblematic nor an uncontested concept (Myers et al. 1998; Mirza et al. 2008; van de Ven et al. 2005). Some, for instance, might take exception to its implicit support for ‘normalisation’, a concept concerned with how disabled people can ‘slot’ into ‘everyday living’ and lead an ‘ordinary life’ (King’s Fund Centre 1980, 1988). Popular in the 1980s, this concept has since been criticised for overlooking the social construction, and socially constructed meanings, of ‘disability’ and ‘normality’ (Chappell 1992); indeed, by not focusing on deconstructing the meanings attached to disability, writers from critical disability studies may argue that it misses that which should ground our approach to disability (Corker 1999; Vehmas and Watson 2014). It has also been accused of ignoring the material constraints that impact the lives of disabled people, problematising rather than valuing difference, and requiring individuals to ‘fit in’ to an unchanged society rather than requiring a changed society to be ‘fit for’ the individual (Chappell 1992; Myers et al. 1998; Pothier and Devlin 2006; Vehmas and Watson 2014; Ward 1992).

Such concerns aside, given the apparent importance of community reintegration to stroke survivors it is troubling that so many find it difficult and challenging (Pang, Eng, and Miller 2007; Robison et al. 2009; Wood, Connelly, and Maly 2010). A study with 434 stroke survivors interviewed 6 months post stroke found that 39% reported a limitation in self-care (bathing, dressing, grooming and feeding), 20% reported difficulties in walking and negotiating stairs, 54% reported limitations with instrumental activities of daily living (e.g. housework, shopping and preparing a meal) and 65% reported restrictions in reintegration into community activities (e.g. social and recreational activities, moving around the community and having an important activity to fill the day) (Mayo et al. 2002). A study with 105 stroke survivors found that, between three and six months post stroke, 83% perceived restrictions in their participation in everyday occupations, defined as activities people need and want to do, such as household chores, work or work-related activities, travel, leisure and social activities (Bergström et al. 2015).

Suggestive of the status and influence of the medical model of disability (Brandon and Pritchard 2011; Schuelka 2015), studies have considered the role of various person-related factors in aiding and/or impeding community reintegration including physical function (Carter et al. 2000; Ostir et al. 2005), mental health (Carter et al. 2000), cognitive ability (Robison et al. 2009), self-efficacy (Pang, Eng, and Miller 2007) and self-awareness (Leung and Liu 2011). Certain factors external to the individual, including social and professional support, have also...
attracted a degree of attention (Chau et al. 2009; Ellis-Hill et al. 2009; Nicholson et al. 2013; Robison et al. 2009; Walsh et al. 2014). Compared with these factors, the physical environment – defined here as the objective and perceived qualities and characteristics of the physical settings in which individuals spend time (Van Van Cauwenberg et al. 2011) – although pertinent (Lord and Rochester 2005), appears critically understudied.

On the relevance of the physical environment, home modifications and equipment have been identified as valuable to stroke survivors (Gustafsson and Bootle 2013; Schulz et al. 2012) whilst returning to the familiar home environment is recognised as a key milestone in recovery and a major source of motivation (Wood, Connelly, and Maly 2010). Studies suggest that stroke survivors view the home as a safe place, an environment in which they feel comfortable and confident (Reed et al. 2012). However, within the home, narrow doorways, stairs, absent handrails, heavy doors and limited space have been found to complicate movement, with poorly designed baths, showers and toilets impeding washing and personal care (Brookfield et al. 2015; Reid 2004; Schulz et al. 2012). Outside the home, uneven surfaces and absent handrails have been found to contribute to trips and falls (Reid 2004) and/or a fear of falling (Robison et al. 2009). Either may slow a person’s walking pace (Lennon et al. 2013) and/or influence an individual’s willingness to go outside (Barnsley, McCluskey, and Middleton 2012; Lennon et al. 2013; Robison et al. 2009). Indeed, research suggests that stroke survivors can consciously adapt their participation in valued activities in response to perceived/experienced environmental limitations (Robison et al. 2009). Highlighted by several of these examples, where research has considered the physical environment, attention has often focused on how it might frustrate community reintegration.

Taking a different tack, in this study the physical environment was conceived as a potentially positive resource capable of supporting community reintegration by providing settings in which individuals can, perhaps are encouraged to, interact with others and undertake various functional, social and recreational activities. Several factors structured this conceptualisation. First, findings from non-stroke populations which suggest that certain environmental details are associated with participation in the community and everyday activities were noted. For example, proximity to recreational facilities has been linked to participation in recreational physical activity in older adults (Berke et al. 2006) whilst proximity to retail facilities has been linked to recreational walking (Michael et al. 2006).

Second, models of disability which, whilst diverse, share the view that the physical environment influences participation and the performance of everyday activities were considered. This included the biopsychosocial model of disability, which views disability as the outcome of an interactive relationship between intrinsic features of the human body and features of the external environment (Bickenbach 2012, S164–S165), and the social model, which understands disability as a form of social oppression produced by physical, social and economic factors/structures external to the individual (Tregaskis 2002).

Third, theories from environmental psychology which suggest that individuals are inclined to ‘approach’ – enter, explore, be satisfied with and interact with others within – ‘pleasing’ environments were considered (De Nisco and Warnaby 2014; Donovan et al. 1994; Mehrabian and Russell 1974; Vieira 2013). Additionally, research which suggests that stroke survivors limit their contact with environments/environmental factors experienced or perceived as ‘problematic’ was noted (Brookfield et al. 2015; Gustafsson and Bootle 2013; Robison et al. 2009).

Lastly, the conceptualisation was influenced by research from Barnsley, McCluskey, and Middleton (2012) which found that stroke survivors with ‘meaningful destinations’, places
such as pubs, clubs and shopping centres that individuals wished to visit, were more likely to travel outdoors.

Set against this background, the research aimed to identify the environments/environmental factors enjoyed by persons with experience of stroke, whilst not presupposing that these would differ from those enjoyed by anyone else, in order to tease out qualitative insights into the environment’s role in community reintegration. A deeper understanding of the physical environment’s place in community reintegration may lead to the identification of new and effective ways to support stroke survivors to lead self-directed lives of their choosing in the community.

**Study design**

We conducted a qualitative focus group study with 29 individuals with experience of stroke living in Scotland recruited from three community stroke clubs. Ethical approval for the study was provided by a University Research Ethics Committee at the authors’ institution.

**Method**

Focus groups (Krueger and Casey 2000) lasting approximately 30 minutes were held with three community stroke clubs in a scheduled club meeting at a club’s usual meeting place. This approach supported wider participation because individuals were not required to attend a separate focus group and meant that focus group discussions took place in a familiar setting (Bloor 2001). The characteristics, advantages and limitations of the focus group method have been well documented (Brookfield, Bloodworth, and Mohan 2013; Krueger and Casey 2000). Although a verbal method, and conscious of the potential for verbal communication difficulties post stroke, the successful use of focus groups in previous studies with persons with experience of stroke, including stroke survivors (Brookfield et al. 2015; Damush et al. 2007; Sarre et al. 2014) and members of stroke clubs (Ch’Ng, French, and Mclean 2008; Lennon et al. 2013), helped prompt their use. Further, as a qualitative method, focus groups are appropriate for accessing and understanding personal perspectives and experiences, the interest of the research. Within such methods, individuals are able to articulate views and experiences, and construct personal narratives, in their own words; they are not bound by researcher-generated answers, as is the case in, say, a questionnaire (Nicholson et al. 2013). Lastly, with evidence suggesting that individuals can feel supported and empowered to share views and experiences within a group setting, focus groups were thought perhaps particularly conducive to drawing out relevant information (Barbour and Kitzinger 1999).

Noting the potential for post-stroke fatigue (Glader, Stegmayr, and Asplund 2002), whilst wishing to minimise the study’s impact, a 30-minute focus group was judged appropriate. This timeframe influenced the content and structure of the focus group whilst its possible impact on the collected data is considered in the conclusions. The first author acted as moderator. Focus groups were audio-recorded and transcribed. Consent was obtained prior to recording. Detailed field notes, capturing the focus group setting, group dynamics, participants’ contributions and background information were compiled within and immediately after each focus group.
Wishing to understand participants’ enjoyable environments, the focus groups began with a list-building activity with individuals asked to identify environments/environmental factors that made them feel ‘happy’. The goal was to create, as a group, a list of ‘happy places’. It was assumed that ‘happy’ would be a readily and widely graspable concept with participants determining for themselves what it meant. List-building activities can be useful for identifying the range of responses within a group and can allow discussion to move to a ‘deeper level’, with participants asked to engage with the list, reflect on its content, pick out particularly important or valued items and so forth (Krueger and Casey 2015). In moving beyond simple discussion, interactive activities like list building can alter the pace of a focus group and generate new and insightful information (Krueger and Casey 2015). Further, mindful that verbal communication (Pedersen et al. 1995) and the ability to follow fast, multi-party conversations (Carlsson, Möller, and Blomstrand 2009) can be impaired by stroke, but wishing to engage a diversity of participants, it was thought potentially easier for individuals with any such impairments to contribute to the creation of a list rather than to a possibly complex group discussion. The list-building activity indeed proved highly inclusive, eliciting contributions from most participants including those with communication impairments.

Following the list-building activity a short group discussion, facilitated by the moderator, took place. Speaking one at a time to aid comprehension across the group, participants were encouraged to reflect and elaborate on the meanings, significance and experiences located within the listed items.

Participants were encouraged to use a variety of methods of communication within the focus groups (Lock et al. 2005). They were guided to highlight items verbally, to write them down (pens and paper were provided) and/or to refer to a set of provided images. The images, each accompanied by a caption, showed a small set of ‘happy places’ identified within a pilot focus group convened with a fourth stroke club (comprising nine participants) principally to trial the method with the target population. Reflecting findings from this pilot focus group, the images showed: green space, leisure/entertainment venues and a social space for meeting others and people watching (a street café). A further image showed a family. Explaining this latter image, in the pilot focus group enjoyment was found to stem from spending time in particular environments with family. Interactions between social and environmental factors emerged as a strong theme within all focus groups. It is discussed within both the findings and conclusion sections. Participants communicated verbally and through reference to the images. Those with communication impairments were aided by volunteers, other club members and the community support worker. The moderator wrote all identified items in large text on giant sticky notes that were fixed to a large table-top flip-chart placed close to the participants. Noting that aphasia, plus visual and perceptual impairments, can be a consequence of stroke, and that these conditions can have an impact on reading ability (Hoffmann and McKenna 2006), the moderator regularly read out the expanding list to aid understanding across the group.

Of note, given their focus on happy places and enjoyable environments, the focus groups were less suited to identifying problematic environments, disliked environments and the manner in which environments might complicate community reintegration – subjects addressed in certain other studies (see Urimubenshi and Rhoda 2011; Schulz et al. 2012; Lennon et al. 2013; Korotchenko and Hurd Clarke 2014; Robison et al. 2009).
Recruitment

Participants were recruited from three community stroke clubs. Table 1 presents the characteristics of the clubs. Purposive sampling was used to recruit the three clubs. Purposive sampling strategies seek to ‘enhance understandings of selected individuals’ or groups’ experiences’ (Devers and Frankel 2000, 264). To achieve this, ‘information rich’ cases – that is, individuals, groups or organisations that provide the greatest insight into the issue under consideration – are selected (Devers and Frankel 2000, 264). Stroke clubs, being visited by persons with experience of stroke, including stroke survivors, seemed appropriate ‘information rich cases’ for the purposes of the study. Ease of access, in terms of ease and distance of travel to the clubs, and anticipated communication abilities amongst club attendees prompted the choice of the three selected clubs. Some stroke groups in Scotland, led by trained staff, focus on building communication skills and confidence amongst stroke survivors. These groups are operated as a formal service by a stroke charity in partnership with the National Health Service. There are around 100 such groups located across Scotland. The members of these groups were thought less likely to be able to participate in a focus group, whilst operating a focus group in these settings, assuming this was indeed possible, would have entailed disrupting a much-valued service. Differing from these groups, community stroke clubs are independent, member-led organisations that focus on peer support and run programmes of social events and activities. There are over 80 such clubs located across Scotland. The members of these clubs were thought more likely to be able to participate in a focus group. Consequently, three easily accessible community stroke clubs were recruited to the study.

Within the three stroke clubs, to be eligible to take part in a focus group individuals had to attend or volunteer at the club. These individuals, with lived experience of stroke, or with experience of working with or supporting stroke survivors, were anticipated to have relevant experiences and perspectives. Influencing this inclusive approach was Shildrick’s (2012, 36) (not uncontested) argument that we should rethink the view that only disabled people themselves have a right to speak on disability.

Sample

The sample comprised 17 stroke club members, 10 volunteers (a couple self-identified as stroke survivors, although this was not expressly investigated within the research), one
informal caregiver accompanying a club member and one community support worker employed by a stroke charity. Club members appeared to present a range of impairments. For example, approximately nine members demonstrated mild to marked verbal communication impairments whilst six were wheelchair users. Seventeen participants were female and 12 were male, ages were mixed but most club members appeared to be aged 50 years and over. Table 2 presents characteristics of the three focus groups. Appropriate to the research interest, the sample consisted of individuals who were all participating in the community to some degree. The implications of working with this sample are considered in the conclusions. Participants were provided with pseudonyms. In each group, participants were assigned a letter, randomly selected but consistent within a group (L for Group 1, A for Group 2 and C for Group 3), and a number.

**Analysis**

The focus group transcripts, field notes and ‘happy places’ lists created within each focus group were imported into QSR NVivo 10 for analysis (Bazeley and Jackson 2013). An inductive thematic analysis, a common analysis technique employed within qualitative research, was carried out on these texts (Joffe and Yardley 2004). This entails identifying themes – that is, ‘a specific pattern found in the data in which one is interested’ (Joffe and Yardley 2004, 57) – within the text rather than applying a pre-existing coding framework to the text. Appropriate to the novelty of the research interest, an inductive approach is considered useful in new/underexplored areas of study (Joffe and Yardley 2004). Analysis began with line-by-line coding (Beesley et al. 2011). As this process progressed, sub-codes added richness, depth and nuance to the analysis whilst organising themes emerged through the grouping together of related codes to form categories and related categories to form broad themes. Themes and categories identified included physical access, getting out of the house, social settings, the stroke club, enjoyable destinations and activities.

**Key findings**

A core narrative emerged from the three focus groups which highlights both the value attached to processes pertinent to community reintegration, particularly performing instrumental activities of daily living, participating in recreational and social activities, and interacting with family members and others, and the environment’s role in these processes. Briefly, participants enjoyed performing activities such as cooking and baking within the home but found ‘getting out of the house’ particularly rewarding, partly because this provided opportunities to interact with others, with social participation being prized. They enjoyed visiting a host of traditionally popular leisure uses and attractions and were inclined,
keen even, to undertake a range of activities within these settings, physical access permitting. This broad narrative is explored in the following.

Getting ‘out of the house’

Participants enjoyed ‘getting out of the house, going somewhere’ (A4, Group 2) with the ‘somewhere’ appearing to be secondary to the primary act of leaving the home: ‘it could be anywhere just away from the humdrum of your own life’ (L2, Group 1). Somewhat tautologically, individuals left the home in order to be out of the home: ‘well you’re getting out, you’re getting out of the house’ (C3, Group 3). Going out most days was ‘a good intention’ (A6, Group 2), ‘you would try to, you’d try to’ (A4, Group 2), but, for reasons left unexplained, this did not always happen. The notable exception to this clear desire to ‘get out and about’ was the enjoyment some found in home-based hobbies and activities including picture framing, crafting, making and certain instrumental activities of daily living such as cooking and baking. For a couple, these activities were valued because they took one’s mind off everything else. One participant described how this was the case for a stroke survivor who could not be present at the focus group:

What he said was, what I never thought about, was when he’s doing that [picture framing] his mind’s off everything else … he’s never said but he’s in a wheelchair so when you’re sitting for a long time you get sore, what he was saying was it’s something to take his mind off, he didn’t say what to take his mind off but he said it took his mind off, all he thought about when he was doing it was doing that at the time. (A4, Group 2)

Importantly, leaving the home created the potential, much valued amongst the participants and pertinent to community reintegration, to interact with others: ‘seeing if it’s just going to the shops, you’ve got some contact with someone else’ (A6, Group 2). Participants greatly enjoyed spending time and interacting with a variety of ‘others’: friends, family members, new people, members of the stroke club, even pets: ‘dogs definitely come at the top of my happy list, a waggy tail makes you happy’ (L1, Group 1). All groups were, perhaps unsurprisingly, very positive about their stroke club and the opportunities it provided to meet others in similar circumstances, visit interesting places and take part in enjoyable activities. Regarding these activities, the following was commented:

What we have discovered is since getting the bowls and the kurling [a ball game], the fun that we’ve had as a club […] and laughing and encouraging each other has been really special. (A5, Group 2)

Interestingly, one participant reflected that taking part in different activities and visiting new places with the club provided members with stories and conversational gambits that were helpful for building relationships outside the club. This participant, and it seemed others in the group, was concerned that without such stories a person with stroke might struggle to engage with others:

It’s something to talk to someone about as well you know it’s, we’re doing very simple things but they’re actually very enjoyable and OK we put a little bit of competition into it but it’s not competition that’s serious but it’s something you can say you’ve done, because quite often folk will say to you what have you done, mmm nothing […] but the big problem with that is if you say, if someone says to you ‘Oh I’ve done nothing’ and the next time you still say ‘I’ve done nothing’ they’re not going to ask you a third time, so if you’ve got something to talk about. (A4, Group 2)
Social interaction

The priority participants attached to social interaction was underlined in Group 1 where, unprompted, individuals identified ‘company’ (L3, Group 1) as a key unifying theme running through their ‘happy places’ list. This preference for company meant that participants tended to favour visiting places and undertaking activities with others rather than alone; being with others formed a welcome ‘change from sitting on your own, you know’ (L2, Group 1). Indeed, for some, visiting places and/or completing activities alone were actively disliked:

L5, Group 1: Being in the countryside sitting down having a wee picnic yourself, there’s nothing going on.

L2, Group 1: Well you wouldn’t aye, it would be no fun yourself but that’s what we mean company, you need the company.

For a couple, sitting alone watching others was sufficient to satisfy this desire for company: ‘you can sit and watch the world go by […] and see other people […] and you can actually, you’re part of a bigger environment without, you’re not so isolated’ (A5, Group 2). Pertinent here, Groups 2 and 3 suggested that, for some stroke survivors, the need for assistance meant that it was a moot point as to whether individuals preferred being in an environment or undertaking an activity alone. However, Group 1 emphasised the sense of achievement that can come from completing tasks independently. describing a club member’s participation in a sponsored walk, the following was commented:

It was the first time that he’d had since his stroke that he’d had any real independence and he went on this walk […] he had no carer hanging on to him he was completely free so to achieve […] that sense of achievement and getting that medal, I mean look at the picture of you all standing there, you couldn’t get beams any bigger. (L1, Group 1)

The value participants attached to social interaction reflects much previous research which regularly documents the importance of social support and group-based activities to stroke survivors (see Beesley et al. 2011; Damush et al. 2007; Glass et al. 1993; Haslam et al. 2008; Kubina et al. 2013; Lennon et al. 2013; Robison et al. 2009).

Popular destinations

Traditionally popular attractions and leisure uses, including theatres, museums, galleries, restaurants, the seaside, football stadiums, parks, zoos, safari parks, pubs, cafes, swimming pools, cinemas and golf courses, were widely enjoyed. These were the most commonly cited ‘type’ of ‘happy place’. These environments provided individuals with opportunities to reflect on fond memories and, linking to aspects of community reintegration, see family and friends, interact with others and participate in a range of social and recreational activities such as eating meals at restaurants, watching the match and socialising with friends at a football stadium or pub and seeing a show at the theatre. Visits to these places formed a much-appreciated interruption to ‘normal life’ (L2, Group 1): ‘a change is as good as a rest’ (L1, Group 1). Unlike some previous research which has found that discomfort, perceived stigma, reduced confidence, anxiety and shame can limit a stroke survivor’s willingness to leave the home and/or engage in previously valued activities, particularly in public settings (Gustafsson and Bootle 2013; Robison et al. 2009), participants appeared keen to ‘get out’ and participate in various activities in diverse public settings.
Noting that persons with stroke can have a lower threshold for stimuli (Daemen, Van Loenen, and Cuppen 2014), it was perhaps unsurprising that Groups 1 and 2 discussed the enjoyment found in calm, peaceful settings. The countryside, parks, ‘nature’ and rural environments were thought to project these qualities. Such environments allowed individuals to relax, unwind and escape ‘the rat race’ (L1, Group 1) and facilitated easy conversation. Individuals were not obliged to fight against traffic and background noise to be heard. Participants in Group 2 directly linked the enjoyment of peaceful, calm environments to recovery from stroke. Following a stroke, some participants reported how ‘busy environments’ caused stress and that ‘stress-free’ environments were favoured (A5, Group 2):

A5, Group 2: I think what you want especially if you’ve had a stroke you like calmness.

A2, Group 2: Oh aye.

A5, Group 2: It’s quite important after you’ve had a stroke, whether it’s a major or minor stroke, I think you find that you want […] a calmer environment and if it’s a busy environment it can actually stress you so you want a stress free environment.

One participant reported that stroke had negatively affected his ability to distinguish between different voices and filter out background noise. Peaceful environments, which could encompass the stroke club, were valued because they made these tasks easier:

For some strange reason background noise becomes main noise for me so if you’re speaking and someone else is speaking both come in and it’s, for some reason you’ll be able to blank out somebody else and then do it but I can’t do that, so a lot of these sort of peaceful environments aye that’s, you come into the stroke club, that’s something that is good. (A4, Group 2)

**Poor physical access**

Reflecting past research (Hammel et al. 2006; O’Connell et al. 2013), poor physical access was found to inform where some individuals could go, felt able to go, their participation in activities and, it seemed, their enjoyment of an environment. Matching past findings (Imrie and Kumar 1998), individuals reported spending time investigating unfamiliar environments: ‘it’s well worth sussing out first what’s suitable for your disability’ (C4, Group 3). Individuals would call ahead to determine access arrangements. Places without step-free access were avoided, it was a case of ‘forget that then’ when steps were present (L1, Group 1). This could mean that environments enjoyed by many were, to all intents and purposes, out of bounds or off limits. Participants readily reeled off specific places to avoid because of poor access. Shops without lift access were ‘not very convenient’ and largely ‘inaccessible’ to wheelchair users (C3, Group 3). One participant described the trials and tribulations involved in accessing a first-floor restaurant from the ground-floor retail space in a shop without a lift. When visiting the shop with a stroke survivor who used a wheelchair, she reported how they were required to exit the shop, journey around the block on which it was situated and then re-enter the building from a rear entrance. Cluttered spaces required individuals to ‘dodge things’, making movement more problematic (A4, Group 2). In contrast, spacious environments provided individuals with ‘a bit of area to move, you haven’t got people close to you’ (A4, Group 2). Such environments were welcomed. Other research with stroke survivors has found a similar interest in spacious environments (Brookfield et al. 2015). Unmade paths proved problematic and hindered the progress of individuals with mobility impairments. This could make rural environments inaccessible. Group 1 worked around this problem by organising a canal-boat
ride through a rural setting: ‘it’s accessible countryside for everybody because we were on the boat’ (L3, Group 1). Adequate accessible toilets were an absolute necessity: ‘on a day out the first thing you’ve got to do is make sure there’s toilet facilities to suit a wheelchair or to suit disabled and a lot of places don’t have that’ (C7, Group 3). Places without accessible toilets were avoided. It was noted that many places lacked this facility or the facilities on offer were unsuitable: ‘at one time the disabled toilet … you had to go down a couple of steps, well it’s not any good if there’s a wheelchair’ (C3, Group 3).

**Conclusion**

In line with past research, focus group discussions with 29 persons with experience of stroke revealed participants’ strong desires to spend time outside the home (Hammel et al. 2006; Lord et al. 2004), interact with others (Salter et al. 2008) and engage in a variety of functional, social and recreational activities (Kubina et al. 2013; Wood, Connelly, and Maly 2010). Such findings further affirm the importance to stroke survivors of processes pertinent to community reintegration (Robison et al. 2009; Wood, Connelly, and Maly 2010), where community reintegration is understood as an individual’s return to functional, social and recreational activities and interactions with family members and others (Pang, Eng, and Miller 2007). In doing so, the findings once again underline the pressing need to tackle problems of difficult and unsatisfactory community reintegration (Mayo et al. 2002; Walsh et al. 2014). For rehabilitation programmes, this might suggest that the focus should widen beyond the current concern for physical function to include a concern for social, and perhaps economic, participation (Wood, Connelly, and Maly 2010). The findings perhaps also raise questions for commentators, such as those from critical disability studies, who, finding problematic or objectionable the ideology underpinning rehabilitation, appear to query the ethics of supporting/encouraging disabled people in their return to these processes (Meekosha and Shuttleworth 2009; Pothier and Devlin 2006; Shildrick 2012).

Multiple specific (e.g. theatres, parks, cinemas, cafes) and more general (out-of-the-home) ‘enjoyable environments’ provided settings in which persons with experience of stroke were able and willing, keen even, to interact with others and participate in diverse social and recreational activities whilst the home was the setting for various enjoyable instrumental activities of daily living (e.g. cooking). Such findings suggest that a range of physical environments, from the public to the private, from the indoor to the outdoor, are favoured by persons with experience of stroke and might have a positive role to play in community reintegration. For policy and practice, this might mean that health professionals should be encouraged to develop, with stroke survivors, person-centred rehabilitation and goal-setting strategies that identify these ‘enjoyable environments’ and detail ways to incorporate contact with them and/or improve the quality and quantity of any existing contact. It might also mean that policies and initiatives should be created to support stroke survivors in accessing these environments. The campaign and event ‘Disabled Access Day’ is a UK-based example of an initiative with pertinent aims. It strives to encourage disabled people, together with their friends and families, to explore somewhere new, identify the most accessible businesses in Britain and promote the commercial value of the ‘purple pound’ (Disabled Access Day 2014).

Confirming past findings (Robison et al. 2009), and reflecting the premise of the biopsychosocial model (Bickenbach 2012), interactions between person-related factors and environmental factors were found to inform an individual’s perceptions, experience, use and, it
seemed, enjoyment of the environment. Calm, peaceful settings were imbued with new value, a finding reflected in research by Carlsson, Möller, and Blomstrand (2009), whilst stairs and small or cluttered spaces became problematic. Negatively effecting community reintegration, and once again highlighting the palpable effects of the built environment on the daily lives and lived experiences of disabled people (Imrie and Kumar 1998), poor physical access and/or the absence of appropriate facilities (e.g. accessible toilets) could limit an individual’s ability to participate in certain functional, social and recreational activities. It seemed that limitations arising from disablement, as opposed to those arising from impairments (a phenomenon termed ‘impairment effects’ by Thomas [2004]), were particularly important, then, in structuring where some individuals went and what they did. For policy and practice, such findings underline the work that still needs to be done to challenge ‘disablism spatial organization’, and the ‘discriminatory social practices’ which create and sustain it (Korotchenko and Hurd Clarke 2014, 432), six years on from the Equality Act 2010, 11 years on from the Disability Discrimination Act 1995 and 46 years on from the Chronically Sick and Disabled Persons Act 1970. They raise questions about the scope and operation of these Acts (Imrie and Kumar 1998; Imrie 1999), and whether, to successfully address access problems, further legislation or better implementation of existing legislation is needed.

Although not an original aim, the study has, in line with past research, highlighted the value of peer support – in particular, participation in a stroke club – to persons with experience of stroke (see Beesley et al. 2011; Carlsson, Möller, and Blomstrand 2009; Damush et al. 2007; Ch’ng, French, and Mclean 2008; Kessler, Egan, and Kubina 2014; Lennon et al. 2013; Lock et al. 2005; Mayo et al. 2015). Addressing an overlooked area, with stroke clubs being an understudied variety of peer support (Morris and Morris 2012), the study found that these groups were valued for providing individuals with opportunities to meet others in similar circumstances, visit interesting places and take part in enjoyable activities. Clubs were fun, informal spaces where members often related to one another through humour and felt comfortable discussing issues, sharing experiences and passing on advice. Put simply, stroke clubs emerged within the research as a ‘good thing’. They may emerge as anything but this, however, if viewed through the lens of critical disability studies. Rejecting binary distinctions, which are identified as both socially constructed and a mechanism for creating difference, maintaining dominance and obscuring connections between people with and without impairments, critical disability studies scholars might be expected to find objectionable, and identify as an artefact of modernism’s ‘othering’ conceptualisation of disability, the idea of establishing a club based on a persons with stroke/persons without stroke dualism (Vehmas and Watson 2014).

This concern/critique notwithstanding, given their form and function, stroke clubs seem potentially suited to addressing the ‘social disintegration’ (Astrom, Asplund, and Aström 1992) – that is, reduced contact with neighbours, friends and others, decreased socialising outside the home and failure to sustain or restore social ties – that many stoke survivors experience (Astrom, Asplund, and Aström 1992; Salter et al. 2008; Viitanen et al. 1988), and may be useful for tackling the lack of meaningful activity that many stroke survivors report, which can lead to boredom, frustration and even depression (Mayo et al. 2002, 2015). Given these potential capacities, in terms of policy and practice, health professionals and others could be encouraged to signpost existing clubs to stroke survivors – previous research has found limited knowledge of community-based groups, services and activities amongst this population (Beesley et al. 2011; Hammel et al. 2006) – and actively encourage attendance,
perhaps by including club visits in person-centred rehabilitation strategies. The benefits of stroke clubs could also be better highlighted to policy-makers, grant-awarding bodies and service providers to encourage their proactive support of new and existing clubs through grants and/or in-kind assistance. In recent years, several stroke clubs have lost public and/or charitable funding, sometimes resulting in their closure (Bareham 2013; Newstead 2009).

When reflecting on the findings, the profile of the participants and the influence of the research method must be taken into account. All participants were sufficiently competent, confident and comfortable to leave their homes and attend on their own a stroke club that met in a public setting and undertook outings to diverse public places. The perspectives and experiences of these individuals may well differ from those presenting lower, or indeed higher, levels of community reintegration (Lord et al. 2004). Individuals presenting lower levels might have found it more difficult to identify enjoyable environments because they might be expected to find more environments problematic and/or experience more environmental barriers. Research focused on understanding possible environmental barriers to community reintegration, not the specific concern of this study, would certainly need to engage with these individuals. Turning to the research method, the use of short 30-minute focus groups, and the concern with building up lists of enjoyable environments, might have led to a smaller, less layered data-set than might have been possible in a longer, more traditional focus group. Here, participants would have had more time to discuss and develop points.

Acknowledgements

The authors thank the participants and stroke clubs who kindly took part in the study. They also thank the wider Mobility, Mood and Place research team.

Disclosure statement

The authors declare no known/perceived conflicts of interest.

Funding

This work was supported by the Engineering and Physical Sciences Research Council under the Lifelong Health and Wellbeing Cross-Council Programme [EP/K037404/1]. The raw data associated with this publication contain personal/sensitive information and cannot be released.

References


