

Elizabeth Mary Heyworth-Thomas

University of Wolverhampton Business School, UK

Rosalind Jones

University of Birmingham, UK

Abstract

This article contributes to research of vulnerable communities and investigates the role of social enterprise created or saved from closure by social entrepreneurs affected personally by a life-changing event, in the context of stroke survival. Qualitative research is deployed to investigate the ways in which social enterprise supports survivors of stroke and their caregivers. Research analysis identifies start-up motives and challenges faced by social entrepreneurs and highlights how social enterprise can bridge the gap in support provision provided by the statutory and third sectors. Involvement in stroke clubs was found to be a key positive contributor to participants' life after stroke. This study has found that those who become social entrepreneurs after a life-changing event exhibit altruistic behaviours, while engagement between these social enterprises and this vulnerable group created specific benefits for vulnerable individuals and their caregivers, highlighting the potential for social enterprise to bridge the gap between statutory and third sectors which is currently overlooked in existing policy provision. The article concludes by making detailed recommendations for future research in this context and for governments and policymakers.

Keywords

caregiver support, personal support network, rurality, social enterprise, social entrepreneurship, stroke support

Social Enterprise: Bridging the Gap between the Statutory and Third Sector

Introduction

This paper contributes to growing research of social enterprise and entrepreneurship. Empirical findings reported here are for part of a larger 7-year qualitative study which explored the everyday lives of survivors of stroke and their caregivers in Wales, United Kingdom (UK). Involvement in stroke club (social enterprise) was found to be a key positive contributor to participants' life after stroke. The aims of the paper are to explain the ways in which social enterprise supports survivors of stroke and their caregivers. In so doing, the paper identifies start-up motives and challenges faced by social entrepreneurs and highlights how social enterprise can bridge the gap in support provision provided by the statutory and third sectors. Current literature considers social entrepreneurs to exhibit antipathy to the state, whereas this study has found that those who become social entrepreneurs after a life-changing event exhibit altruistic behaviours which go beyond philanthropy. The way in which these social enterprises engage with this vulnerable group in this context, highlights their potential for bridging the gap between statutory and third sectors which is often overlooked in existing policy provision.

Public awareness of stroke has increased over recent years due to the rise in awareness campaigns in the media. It is the third largest killer of adults and the largest cause of adult disability in the UK (Kumar et al., 2015; The Stroke Association, 2016; Welsh Government, 2016; Williams, 2008). Stroke has largely been researched by those in the medical field who seek to improve stroke survival rate and reduce the rate of stroke incidence. One-third of people who experience a stroke survive with varying degrees of long-term physical or neurological disability often with changes to psychological and emotional wellbeing and, social participation (Ekstam et al., 2011). Survivors often experience one or more of these negative side effects post-stroke, the impacts of which, can remain or, vary in severity in the months and years after a stroke. As a consequence, everyday activities which might usually be taken for granted often become daunting tasks requiring more effort and possibly assistance. There are approximately 7,600 stroke incidences in Wales each year (Welsh Government, 2017), 6,000 of which are new stroke incidences (Welsh Government, 2016). Public awareness and medical advancement have led to quicker diagnosis and more effective treatment, resulting in an increase in people surviving stroke each year. Therefore, the number of people living with the impact of stroke in their everyday lives has also risen (Ashton et al., 2010; Glasby, 2017). Furthermore, as survivors are (typically) cared for by family members (Cameron et al., 2013; The Stroke Association 2016), the increase of stroke survival means that there is a rise in the number of family members becoming primary caregivers. As family members transition into the caregiving role, they themselves experience changes to their everyday lives. These changes are not only physical. Caregivers are reported to experience feelings which are commonly reported by survivors, such as depression and anxiety (Jaracz et al. 2015), fear (Sklenarova et al., 2015; White et al. 2014) anger and frustration (Auton et al., 2016; Jaracz et al., 2015). This highlights the need to support caregivers as they then become patients in their own right, with their own needs.

The rise in stroke survivors and caregivers places increased pressure on statutory sector support. The rural infrastructure of Wales also adds further complexity compared to urban regions, as rural communities face challenges with service accessibility and sparse support availability as well as increased travel time for statutory sector home care provision (McGrail and Humphreys, 2015; Williams, 2008). Policymakers are also challenged with defining rurality across the UK as Rurality itself cannot be simply defined. While dictionaries define rurality as countryside; geographers define rurality by land use, population density and terrain. Rurality may be further defined by distance to services such as the public transport system or the nearest shop, whereas the United States (US) defines rurality in terms of exclusion (US Census Bureau, 2007). In order to find the most appropriate definition, we define rurality using the guidelines of the Wales Rural Observatory, identifying rural counties as those with a population of 150 people or less, per square kilometre (Radcliffe, 2011). By this definition, 40.91% of counties in Wales are considered rural (StatsWales, 2018).

Firstly, the paper reviews the relevant literature. Secondly, the methodology is detailed which includes discussion of the qualitative research approaches deployed in the study. Thirdly, the findings are discussed based on research evidence from six stroke clubs including observations and interviews. The paper concludes by summarising the key themes, providing practical and theoretical implications together with recommendations for further research. Recommendations are also made for governments and policymakers to facilitate and support social enterprise as a key contributor to the personal support networks (PSNs) of survivors and caregivers.

Literature Review

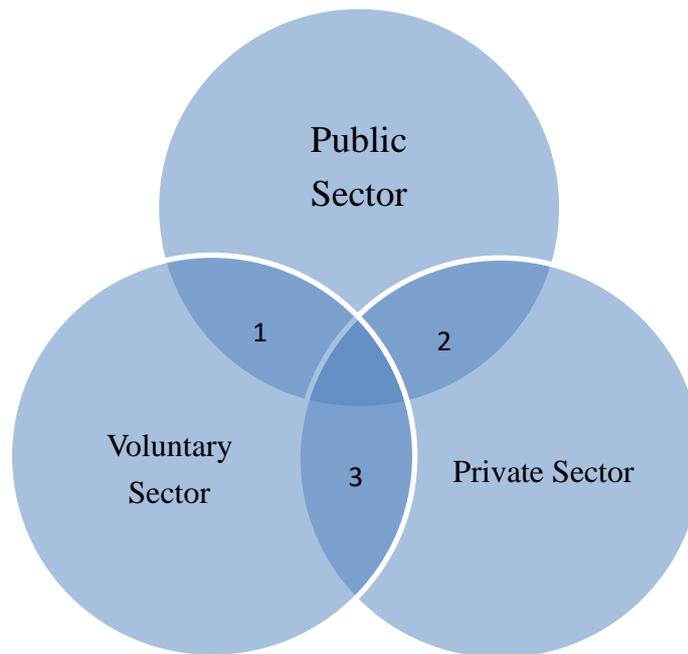
Current discourse within the entrepreneurship literature distinguishes social enterprise and entrepreneurially-led enterprise by the intended outcomes. Bjerke (2013) defines social entrepreneurship to be all entrepreneurial activity which aims to benefit society through social aims. Ridley-Duff and Bull (2016) expand upon this, defining social enterprise as an enterprise which is not primarily driven by financial return. Instead, the social

enterprise primarily focuses on social objectives with any profit made, being reinvested into the organisation in order to further work towards social aims and, for the social business to remain sustainable. Chell (2007:18) redefines the notion of entrepreneurship with a holistic definition so that it is applicable to both social and economic enterprises, describing entrepreneurship in this context as the process of opportunity recognition and pursuit with a view to create value. From this viewpoint, entrepreneurs (both social and economic) consciously seek resources which can be aligned (such as through networking and other processes) and use their personal or 'human capital' in order to achieve their mission of wealth and social value creation. Martin and Thompson (2010) describe social enterprise as harnessing a triple bottom line: social aim, income generation, and economic impact. This makes social enterprises, therefore, a useful strategic partner for policymakers to consider.

Scholars have evidenced the role of entrepreneurial responses and enhanced provision of new products or services which occur via social enterprises in response to urgent social problems, using innovative Schumpeterian behaviours (De Fournay, 2001; Schumpeter 1934). Where traditional, private, or, statutory sectors are unable to provide satisfactory solutions, this can be observed where homogenous groups of people with similar needs form or renew social enterprises to address unmet need(s) in society. More recently, the notion of social enterprise has further evolved. The literature describes social enterprise as a product of the third sector where the 'grey' area of cooperative and non-profit trading practices have occurred; or, as a result of the integration of the private sector into the third sector (Ridley-Duff and Bull 2011: 2016). These authors consider social enterprise to be 'a product of the tension between attempts to reform the public (statutory) sector through the introduction of private sector management rhetoric, and radical responses to those attempts by local politicians and community entrepreneurs with socialist sympathies' (Ridley-Duff and Bull 2011: 39). This statement by Ridley-Duff and Bull refers to the change in attitude towards economic theory around 1970 which impacted on entrepreneurship research worldwide; where there was a noticeable increase in small enterprise and innovation in leadership and the social economy, suggesting that social enterprise expanded out of liberal capitalist ideas which founded the principles of 'new public management' and market socialism (Chandler 2008; Ridley-Duff and Bull 2011: 2016).

Focusing on the drivers of social enterprise, we refer to Leadbeater's (1997) model of cross-sector social entrepreneurship that creates social capital, cited in Ridley-Duff and Bull (2011: 73). This model (Figure 1) identifies the darker shaded areas, the crossover areas, as the 'social entrepreneurs' sector.

Figure 1: Leadbeater's model of cross-sector social entrepreneurship that creates social capital



Extracted from Ridley-Duff and Bull (2011: 73)

Leadbeater's model (1997) asserts that social enterprise is a 'bridging sector' which provides an opportunity to utilise skills, abilities and knowledge. Ridley-Duff and Bull (2011) describe that the bridge at intersection 1 shares a public interest, and so lays foundations for non-profit enterprise. At intersection 2, there is an element of corporate responsibility where government bodies do not consider the voluntary (third) sector as a viable business partner for delivering public service. Intersection 3 then identifies the gap between the private (independent) sector and the voluntary sector as a 'more than profit' spectrum. Here, antipathy to the state is considered the driver for these businesses who seek to meet the needs of disadvantaged communities, seeing themselves as realistic about the statutory sector's capacity to oppress minorities. The centre crossover is the overlap of all sectors; being 'idealist' it replaces private, public and voluntary competition with a democratic multi-stakeholder model where all interests in a supply chain are acknowledged to break down barriers to social change. This model proposes that social enterprise in the third sector can be supported by the independent and/or the statutory sector. With more traditional forms of funding being cut, entering the sector of social enterprise creates opportunities for third sector organisations (TSOs) to become sustainable and continue to produce collective benefits, operating similarly to an independent sector business (Laville and Nyssens 2001; Ridley-Duff and Bull 2011; Yu 2011). Therefore, by becoming a social enterprise, insecure provision such as charitable donations and voluntary staff are less relied upon (Seanor et al., 2013).

Research Methodology

Biographical narrative interviews, semi-structured interviews and unstructured observations informed the findings of this study. A humanistic interpretivist approach to inductive qualitative research allowed participants to describe interpretations of their own social world (Bernard, 2013; Gray, 2013). A multi-stage research design was carried out in the manner of a longitudinal study, allowing for identification of any change over time, and allowed for triangulation and data checking (David and Sutton, 2011; Gray, 2013; McGivern, 2013).

The study sample

Purposive sampling (McGivern, 2013) was used to recruit 6 stroke clubs out of 50 across Wales. The sampling criterion was that the stroke clubs were to be located in Wales, UK. The host of each observed stroke club was invited for semi-structured interview. Then, survivor participants and their caregivers were recruited for interview from each of the stroke clubs. A multi-case approach to survivor and caregiver participants allowed for survivors and caregivers to be considered as their own unit, and allowed for cross-comparisons between cases. 2 of the 8 cases consisted of a survivor participant while the remaining 6 consisted of a survivor and

caregiver dyad. This purposive sampling strategy provided an opportunity to explore a specific community suitable for meeting the study aims.

Data Collection

The semi-structured interview questions focused on the hosts' start-up motivation, member recruitment, financing, marketing, challenges faced and delivery of the stroke club provision. The survivor and caregiver interviews focused on the participants' everyday life after stroke. Each stroke club was then observed 4 times, bi-monthly. Non-participant observation of stroke clubs generated further insight into member behaviour, relationships between members and the behaviours and relationships between members and volunteers were observed, as well as the activities which took place. This produced insight into similarities and differences in activities and, delivery between the different clubs observed. Survivor and caregiver dyads were interviewed following Wengraf's (2009) Biographical Narrative Interpretive Method (BNIM). The only deviation was when survivors with communication issues required a more direct approach to enquiry, for this an alternative template was formed. These interviews focused on the everyday lives of study participants and provided insight into their perspectives' of stroke club (as members) as well as identification of the key actors, networks and support services involved in the everyday lives of the participants. The interview data contributed to the observation data making an invaluable contribution to the methodology (Green and Thorogood, 2009). 6 of survivor and caregiver dyads were revisited for follow-up interview 6 months after the first which, using the BNIM format, further explored key findings from the first interview, and identified any change since the first interviews. The remaining 2 did not participate in the follow-up interview due to the death of a survivor (1) and a non-response to the follow-up request (1).

The primary data collection methods were synergistic, complementary, and allowed for triangulation of the data through cross-referencing of the data collected, and the literature review. This helped validate the data, ensuring that robust, reliable data added strength to the research findings (McGivern, 2013). Biographical narrative interviews and semi-structured interviews were piloted during the first interview. The same process was followed for follow-up interviews with survivor and caregiver participants.

Data Analysis

Raw data was transcribed and stored using a Computer Assisted Qualitative Data Analysis Software (CAQDAS) package, Nvivo. The transcripts were coded using nodes; categorising data into themes. Self-transcription of the interview data allowed immersion within the data. This first stage of data analysis aided data recall during coding and analysis, ensuring that common themes were identified during the transcription and coding phases (McGivern 2013). Summary nodes were used to first code the data. It was then further coded using sub-nodes reduce the categories further, making them more defined. Axial codes then linked the coded data (the data within each node category) to one another, highlighting patterns across the data. The data collected from survivor and caregiver dyads was coded independently of the stroke clubs in order to adhere to data confidentiality, as stroke clubs could be possible identifiers for the participants. For this reason, the findings are presented from the 2 data sets. This data reduction strategy organised raw data into manageable sections. This process was replicated across the multiple primary data sources, preparing the raw data for analysis. As themes were identified within the primary data, the author revisited the data source a second time, to ensure that all themes were considered in the coding process. This strategy ensured academic rigour and enabled both a priori and emerging themes to be considered.

Coding raw data as a node itself allowed triangulation of data through exploration of nodes and themes across individual and multiple data sources. This process identified common and independent themes, highlighting areas for further exploration and contributed to survivor and caregiver follow-up interview development. Furthermore, identification of literal and underlying themes reduced the risk of hidden meanings being overlooked, particularly in relation to the biographical narrative interview data. This process ensured validity and reliability of data, which produced rigorous findings.

Findings

Table 1 provides a breakdown of each stroke club observed and details the stroke club hosts. Each host had experienced stroke in their lifetime. Either personally, in their professional capacity or, as caregivers.

Table 1: Stroke club characteristics

Stroke Club	SC Host descriptor	Host Interviewed	Meeting Frequency	Meeting time	Number of Members (inc. volunteers)	Estimated age of Members (exc. Volunteers)	Cost to Members (exc. Transport and Raffle)	Transport to and from venue (survivor only)
SCA	Survivor	Yes	Monthly	12.00 pm – 3.00 pm	39 – 47	50+	-	Car, Taxi, Red Cross mini bus
SCB	Ex-Speech Therapist		Weekly	2.00 pm – 4.00 pm	12 – 20	35+	-	Taxi
SCC	Survivor		weekly	10.30 am – 3.00 pm	41 – 60	30+	£1.50	Car, Taxi
SCD	Caregiver		Weekly	10.30 am – 3.00 pm	17 – 21	35+	£5.00	Car, Taxi, Walk
SCE	Caregiver	Yes	Fortnightly	2.00 pm – 4.00 pm	24 – 37	45+	50p	Car, Taxi, Walk, Own mini bus
SCF	Widow (previous caregiver)	Yes	Monthly	1.30 pm – 3.30 pm	3 – 6	45+	-	Taxi

Semi-structured interview with stroke club hosts

Hosts from stroke clubs A, E and F were interviewed. The host from SCA explained that her motivation to form the club came from her own unmet need whilst recovering from stroke: “I couldn’t keep working, but I couldn’t just sit there and do nothing. I’d have been bored and felt useless. So I asked the nurse if there was a club or something for others in my position, she said there was nothing. So I just decided to start one myself and see if it would take off”. 12 years on, SCA had gained over 50 members. This highlights the motivation to start a stroke club and demonstrates a need for such support in the community. Stroke clubs B-F were already established when the hosts took over. Initially run by a TSO with funding from the local authority (LA), stroke clubs B-F faced closure when statutory funding was withdrawn. Stroke club members were reported as being tearful, distressed and upset when they learned of the impending closure “for some, it is all they have, and the only time they get to see anyone other than their carers” (survivor participant). The SCE host commented “we all want to support one another, the stroke people and us as family and caregivers. It can be hard, especially when your husband cannot talk to you because of stroke. There are a few here that cannot talk, and us caregivers would go potty in a week if we didn’t have people to talk too!” This highlights the emotional support that the host gains from running stroke club.

The foreseeable closure of stroke clubs B-F led to existing members forming committees and taking over the running of the stroke clubs themselves. Stroke club formations were similar and consisted of a host and founder, a treasurer, a member’s secretary and club volunteers. Seeking ways to become self-sufficient, the stroke clubs moved away from TSO led clubs, to become social enterprises in their own right. Stroke clubs had the primary aim of supporting vulnerable adults (stroke survivors and caregivers) in their everyday lives. This social aim had positive economic benefit in supporting disadvantaged groups in society, whilst income generation occurs through membership fees and other fundraising activities. This demonstrates Martin and

Thompson's (2010) triple bottom lines of social enterprise and contributes to the reported studies of Ridley-duff and Bull (2016) by noting altruistic and philanthropic behaviour characterised by the stroke club hosts. These behaviours focus not on donation but selfless acts of support to others in a similar situation. Rather than antipathy to the state, this is implicit but purposeful behaviour which is driven by altruism. In doing so, these social entrepreneurs are meeting their own personal need which challenges the widely reported concept of entrepreneurship by necessity and introduces a new definition, of an entrepreneur driven by their own personal needs after a life-changing event.

SCC followed similar growth to SCA. Once a club of 8, expanded rapidly to a membership of over 30 during the 4 years it had been running independently. The host of SCC is concerned "the venue is too small, we might have start turning people away unless we can find a larger, more suitable venue". SCD also saw an increase from 5 members to over 35. The mere expansion of stroke clubs over time illustrates an increasing demand and need for support in rural Wales, with some members travelling in excess of 45 minutes to attend. In terms of member recruitment, SCA, C, and D recruit members (members) via newspaper advertisements and word of mouth. As previously noted, SCB also received members with communication difficulties via a referral scheme from hospitals and local GP surgeries. When asked about the support they receive from external organisations, the stroke club hosts described support from the stroke related TSO as ineffective: "Pfft, it's not worth it! All they do is turn up every once in a while and see what you are doing, give you ideas in a booklet, which you cannot use because they do not help you set them up, and there isn't always enough money to make it work long term.... And then they just then go off....And if you want to raise money, they give you things to help advertise, but then they want half of everything you raise! So, it's not worth the effort in the end. So we just try and raise the money ourselves and keep the lot" (SCE host). As table 1 shows, funds were primarily raised through membership fees for clubs C,D and E. In addition, sale of raffle tickets as well as tea, coffee and snacks contributed to regular income, with fundraising events run by stroke clubs and the local communities adding larger sums on occasion. Monies raised covers venue hire (for clubs A-E) as well as the rehabilitative exercise coach (when booked) with any remaining profit being used for entertainment such as Christmas parties and excursions. The outgoings for stroke clubs varied as growing membership means that some clubs such as SCA and SCC pay for larger venues due to a growing number of members. Whilst this model makes stroke clubs A-E sustainable, SCF with few members is struggled with a venue charge of £20, paid for by the stroke club host. SCF host just asks for contributions for tea and coffee from the members as she recognises that the members are on limited incomes. The SCF host was torn between the challenge of managing a larger club which may be more sustainable and promoting membership recruitment.

Transport to and from the stroke venues was primarily by car or taxi with a small number of members from stroke clubs D and E walking to the venue, a club owned minibus (SCE) which the members who use pay a small fee and a charity minibus (SCA) which charges a small fee for people who use it. Thus, the stroke clubs became social enterprises created with the aim of benefit the local stroke survivor community. However, the key challenge that the stroke club hosts faced was managing their own health needs or caregiving role alongside the running of stroke club, as exemplified by the host from SCA who expressed a desire to run the club each week, but found it would be too much to organise due to her own post-stroke health.

Stroke Club Observation

Scott and Marshall (2005) consider clubs where members (members) are united by a shared experience to be a social club. Although there is a social aspect, this understates the impact of the stroke clubs observed. They offer a stable pattern of interaction, a branch of community, and provide a valuable social and participative outlet. The clubs were of mixed physical and neurological ability and varied considerably in membership size. Despite being stroke specific, it was noted that 2 members from SCD had not experienced stroke; one had dementia and the other had lifelong disabilities. 4 of the clubs were English speaking, with the remaining 2 clubs being bilingual; both English and Welsh. 5 of the 6 clubs were mixed gender with SCF consisting of females only (unintentionally) and 4 clubs consisted of both male and female survivors and caregivers; SCB and D consisted purely of survivors and 3 members of SCF are widowers who have continued to attend after the death of their husbands who were former stroke survivors.

The stroke clubs provided a platform for activities which the survivor participants found beneficial to their rehabilitation and recovery of previous stroke, in some cases, relearning skills lost due to stroke, as well as supporting them with prevention of further stroke. For example, clubs B, C and D offer gentle exercise programmes such as seated exercise to music from an exercise professional. Exercises are based on physiotherapy movements and are interactive. Also, it was a notable observation that the voice exercises (SCB) were facilitated in a way that encouraged participation, for instance, taking it in turns going clockwise around the circle, each person in turn. The clubs also had guest speakers, musicians, organised day trips and various

other forms of entertainment, which contributed to intellectual fulfilment. The range of activities differed for each club. This suggests that although the stroke clubs are meeting the needs of the members in terms of a social outlet and information sharing, there is inconsistency in the activities available. This was particularly noted when a survivor participant stated he wanted more speech therapy but it was not offered this at his local stroke club, whereas if he resided closer to another club that provision would have been available. Members who attended clubs B, C and D described how rehabilitation exercises helped them improve their abilities with everyday tasks and encouraged them to practice rehabilitative activity at home. The re-engagement of motor activities was considered beneficial by one survivor participant, who considered that without such, a survivor “can become even more dependent on their family members”.

All participants were able to explain to the researcher how stroke clubs had provided them with a safe-zone where they can be with people who have a ‘shared experience’. One participant commented “it’s my only real sense of reality because I see people who are far worse than me physically or mentally, yet somehow I’m connected or sharing; they understand me better than people who have not had a stroke”. This participant described how the club had enabled him to come to terms with his stroke: “the comfort I get from stroke club; in accepting the things I can’t do and being grateful for what I can do”. This participant reflected on his own outcome of stroke compared to other stroke club members and takes comfort in having an avenue of social experience which provided a hub for people to share their experience and be around people he could connect with, who understand what he had been through. Survivor participants reported feelings of security in this social setting and a ‘safe zone’ where they can confidently socialise without being exposed to societal stigma. One caregiver reflected: “I think that the club has been really quite important personally because it gave mum (a survivor) quite a significant thing to concentrate on to get out of the house twice a week for which she might not have done and, I think it also gave that to the people that were involved in the setting it up, and actually what it set out to do which was to empower people who have had strokes and to understand that they could continue to contribute that they didn’t have to be passive participant sort of thing that they could still have skills and experiences that could be used but it is a really, really difficult thing to do”.

A caregiver participant reflected that she did not think her husband was: “going to live to get here”; to his current stage of rehabilitation, commenting that he was a “different man before stroke club”. A committee member and founder member of SCD observed “there is a life after stroke, it won’t be the same, but there is” and noted how the club helped members to regain their confidence and self-esteem. A caregiver also observed that there was a lack of stroke-specific rehabilitation and opportunities to gain ongoing support after hospital discharge. She explained: “the services stopped a little soon in that they do tend to concentrate on the very basics of personal care” and felt that there needed to be a deeper level of rehabilitative support which focused around participation in the wider environment: “not just enabling them to return home”. A caregiver also felt that being rural meant that “services were more dispersed and harder to access than perhaps they would be in urban areas”. Whilst another felt that “the services are there, it just costs more money for transport to access them”. A participant who lived approximately a 45-minute drive from his nearest stroke club is now only able to attend on rare occasions due to post-stroke fatigue, highlighting that the impact of stroke itself can be a barrier to engagement in appropriate support provision, particularly when there is increased travel time to such provision. This emphasises some of the issues for people living in rural communities who seek such support. His wife (and caregiver) commented: “it’s just too far really, it takes so much out of him but they do keep in touch”.

Findings from interviews with survivor and caregiver participants

A common mission of the stroke clubs was to provide support to people living with stroke and create a place where people can socialise with people who have the shared experience, in a safe environment where they feel that they are away from any risk of stigma. Survivor and caregiver interviews identified stroke clubs as a key contributor to personal support networks (PSNs), second to that of the support of their caregiver (for survivor participants), and family (for caregiver participants). The social setting of stroke club and their rehabilitative support reduced barriers to social participation which in some cases were self-built (such as perceived stigma) and contributed to improved self-perceptions of post-stroke quality of life. For several of the members, it was the only social interaction they had, with one participant who is dependent on 24-hour care stating that the one day a month she attends SCA is the only time she is outside of the house and interacting with people.

During interviews, participants highlighted gaps in statutory sector provision on numerous occasions. The primary unmet need identified was a lack of, and poor clarity of, information from the third and statutory sectors. Survivor and caregiver participants reported that the availability of information depended on them “asking the right questions of the right people” (caregiver participant). A concern here was that the participants also stated that because the experience was new to them, they did not know the questions they should be asking.

Caregivers also reported feeling as though they had no support in the transition into the caregiving role. The participants recognised that the lack of information about stroke, preventing further stroke and how to care for survivors of stroke meant that they were going into the caregiving role “totally blind”, feeling that “nobody tells you anything” (caregiver participant). The participants also expressed concerns that there was a lack of information on how to reapply for a drivers licence or details of financial support and that this would have been very useful. These examples of lack of information added to the feelings of strain, anxiety, fear and burden to the caregiving role, but also caused strain for the survivor participants. These feelings can lead to other health concerns such as depression and reduce participant motivation in rehabilitative activity. Whilst the statutory sector provides an effective rehabilitative program, survivor participants reported that their entitlement to participate was limited to a specified number of weeks (as medically prescribed to them). This meant that after their entitlement had come to an end, the survivor participants needed to find other ways of being motivated to carry on with activities which may help with rehabilitation, or stop completely. Stroke survivors with speech and language difficulties reported that they felt the speech therapy prescribed upon hospital discharge had ended too soon, feeling that further speech therapy would have provided them with a better outcome. This left them looking for other ways to fulfil their need for further speech and language support. The participants reported that stroke club addressed at least one of their unmet needs. Highlighting the value of stroke club to their post-stroke lives, a caregiver participant reflected on the health of her husband (a survivor participant): “he was a different person before the stroke club”. Whilst a survivor caregiver who suffered with depression commented that stroke club had helped him to come to terms with stroke on a psychological level: “It’s my only real sense of reality because I see people who are far worse than me physically or mentally. Yet somehow I’m connected or sharing. They understand me better than people who have not had a stroke. The comfort I get from Stroke Club; is that it helps me to accept the things I can’t do and be grateful for what I can do”. The data indicated that the majority of information participants obtained came from other people who they had met at stroke clubs, highlighting that they consider stroke clubs as a key opportunity to share experiences, and as an informal route to obtaining practical information and emotional support. Similarly, a caregiver participant reflected on the process of taking over the running of the stroke clubs from the TSO: “it empowered people who have had strokes, to understand that they *could* continue to contribute and that they didn’t have to be passive participant” but acknowledges that running the stroke club “is a really difficult thing to do” as the hosts are running the clubs with their own post-stroke challenges.

During the study, 2 significant events occurred: one research participant club member lost his wife and caregiver. This participant observed that he felt supported by his community and that the stroke club (SCA) had been a great source of support. Another participant’s home was flooded, and her caregiver reported that they, the club (SCD), did not offer any source of support or assistance as such, but reflected that there was not a lot they could have done. This suggests there could be more focus on this social enterprise in terms of community support as to its members outside of the meeting club. Another caregiver observed that she ‘couldn’t cope without the stroke club, and the friends we have gained’ and reflected on instances where the other members of the clubs advised on some of the associated ailments resulting from stroke.

Discussion and Conclusion

This study identifies a different type of social entrepreneur. Those who are motivated by personal need and altruistic behaviour, rather than necessity. That is, people who have become social entrepreneurs to meet their own personal needs and the needs of others, after a life-changing event such as stroke. Such needs are highlighted as informal support through the coming together of a homogenous group of people who share the same experience. Support which continues in the months and years after stroke and is not limited by a rehabilitative period controlled by statutory sector provision and addresses social, psychological, physical and practical needs which were not met by statutory or third sector provision. In doing so, this paper illustrates the value of social enterprise and entrepreneurship in supporting vulnerable adults who are living with critical health conditions, as well as their caregivers. The ownership of these clubs, by people who would normally be considered the service-users is what makes stroke clubs unique, exemplifying what person-centred support run by the community, for the community, can look like.

These social enterprises grew and flourished out of social necessity, position them between public, voluntary and private sectors, meeting a vital need for stroke support for survivors. Confirming findings reported in social enterprise literature, these clubs are all motivated to be self-sufficient and entrepreneurial in their practice, although stroke club hosts did not recognise themselves as social entrepreneurs. This creates a challenge for policy makers wishing to support social entrepreneurs as their lack of self-identification makes them a hard to reach group. The hosts are the driving force behind development and funding of these social clubs. They can relate to post-stroke life and understand end users’ needs and aspirations in a way that policymakers and TSOs might not. Although managing stroke clubs presents personal benefit, the role also holds challenges. Despite

responsibility of managing larger clubs being shared, this on top of the caregiving role and living with the outcomes of stroke such as stroke fatigue meant that it was becoming too much for some hosts, or that they could not run the provision as frequently as they would like. This, combined with the evidence from Leadbeater (1997) suggests that support from other sectors surrounding the social enterprise may be beneficial to social entrepreneurs and to the enterprise itself. However, it is important for any new support for the social entrepreneur to be appropriate and not necessarily focus on financial provision, particularly as most of the clubs had become financially secure.

The stroke clubs are an example of how social enterprise can fill a gap in public service provision in rural areas. They create a safe-zone where people feel they can be themselves and share experiences of life after stroke whilst providing long-term support, away from any perceived societal-stigma. For the study participants, this reduced barriers to accessing the support which were self-built, compared to other social groups. For some, gaining confidence through stroke club led to further barrier reduction for other social groups and engagement in society whilst providing support which is more reliable than informal structures. Collaboration with other organisations within the social enterprise structure could provide further opportunities to regain self-confidence and increase social-participation.

In applying Leadbeater's model (1997) (figure 1) to this context we see that while clubs were funded by the LA they were at point 1 non-profit. When funding was withdrawn and the enterprises became self-funded, with TSO support in the form of fundraising fliers and newsletters, they were placed closer to the voluntary sector on the model. If they were to receive support from other sectors in the future, there could be the opportunity to bring the clubs to the centre of the sphere. Business support in the form of financial skills and marketing could also benefit social entrepreneurs and be sourced from the other sectors of the spectrum. In addition, the health sector could work with social enterprises in this context and provide activities which are beneficial to survivors of stroke and caregivers. This could be incorporated into health and social care policy. There was an inconsistency of activities within the stroke clubs, which suggests that there is opportunity for more focused business strategies as suggested by past researchers (Seanor et al., 2013). A standardised package could be provided to enable rehabilitation activities to be provided at all of the clubs. This could be achieved by coordination of the social enterprises through affiliated activities, which currently, the TSO has failed to instigate. This recommendation would assist in social enterprise development in rural regions. Particularly where the social entrepreneurs have 'lived the experience' and are driven by their own needs to support public sector policy delivery for the social good.

Limitations of this study include lack of generalisability of the findings as a small sample was employed, however, this study provides a detailed and in-depth study to provide new insights into the issues for stroke survivors and those responsible for developing social enterprises out of necessity. Further research is proposed to further investigate management and entrepreneurial processes within such enterprises; to establish the wider issues across rural regions of the UK and beyond and, to examine social enterprise and stroke support clubs in both semi-rural and urban areas. Further avenues for research could include an exploration of social enterprise in the context of stroke support located in urban and also under developed regions to ascertain any similarities and differences by comparison. A further study would also be beneficial to explore how the how stroke services have developed in this area five years after the implementation of the Stroke Delivery Plan (Welsh Government 2017). Wider studies could be carried out globally by replication of this methodological approach.

Implications for policymakers include highlighting the need for continuing and supporting joined-up delivery of support services for disadvantaged clubs and facilitation of social enterprises with support for socially motivated entrepreneurs so that rural society can effectively rise to meet these challenges in times of austerity and retraction of publicly funded services, supporting person-centred care in different countries and regions. The global impact of this, is that such research could also advance policy and support provision in other rural regions and developing countries. Policymakers are recommended to explore non-financial support initiatives which would be more appropriate for social enterprise of this nature. As such, policymakers are also advised to broaden the definitions of social enterprise which exist in current policy, noting that not all social entrepreneurs seek growth or require support by capital. Particularly in terms of those social enterprises that focus on supporting vulnerable communities. This would also further support health and social care policy initiatives to help people to help themselves and contributes to inclusion and community cohesion in rural communities.

References

- Ashton C, Bajekal M and Raine R (2010) Quantifying the contribution of leading causes of death to mortality decline among older people in England, 1991–2005. *Health Statistics Quarterly* 45(1): 100-127.
- Auton, Malcom F., Patel, Kulsum., Carter, Bernie., Hackett, M., Thornton, Tim., Lightbody, Catherine E., Leathley, Michael J., and Watkins, Caroline L (2016), Motivational interviewing post-stroke: An analysis of stroke survivors' concerns and adjustment. *Qualitative health research* 26, No. 2:264-272.
- Bernard R (2013) *Social research methods: qualitative and quantitative approaches*. 2nd Edition. Los Angeles: Sage.
- Bjerke B (2013) *About Entrepreneurship*. Cheltenham: Edward Elgar.
- Cameron JI, Naglie G, Silver FI and Gignac MAM (2013) Stroke family caregivers' support needs change across the care continuum: a qualitative study using the timing it right framework. *Disability and rehabilitation* 35(4):315-324.
- Chandler J (2008) *Explaining Local Government: Local Government in Britain since 1800*. Manchester: Manchester University Press.
- Chell E (2007) Social Enterprise and Entrepreneurship: Towards a Convergent Theory of the Entrepreneurial Process. *International Small Business Journal* 25(1): 5-26.
- David M and Sutton CD (2011) *Social Research: an introduction*. 2nd Edition. London: Sage.
- Defourney J (2001) Introduction: from third sector to social enterprise. In: Borzaga C and Deforney J (eds), *The Emergence of Social Enterprise*. London: Routledge, pp. 1-28.
- Ekstam L, Tham K and Borell L (2011) Couples' approaches to changes in everyday life during the first year after stroke. *Scandinavian Journal of Occupational Therapy* 18(1): 49-49-58.
- Glasby J (2017) *Understanding health and social care*. London: Policy Press.
- Gray DE (2013) *Doing research in the real world*. London: Sage.
- Green J and Thorogood N (2009) *Qualitative methods for health research*. 2nd Edition. London: Sage.
- Jaracz K, Grabowska - Fudala B, Górna K, Jaracz J, Moczko J, and Kozubski W (2015), Burden in Caregivers of Long-Term Stroke Survivors: prevalence and determinants at 6 months and 5 years after stroke. *Patient education and counseling* 98, No. 8: 1011-1016.
- Kumar R, Kaur S and Reddemma K (2015) Needs, Burden, Coping and Quality of Life in Stroke Caregivers A Pilot Survey. *Nursing and Midwifery Research Journal* 11(2): 57-67.
- Laville JL, and Nyssens M (2001) Towards a theoretical socio-economic approach. In: Borzaga C and Deforney J (eds), *The Emergence of Social Enterprise*. London: Routledge, pp. 312-332.
- Leadbeater C (1997) *The Rise of the Social Entrepreneur*. London: Demos.
- McGivern Y (2013) *The Practice of Market and Social Research: an introduction*. 4th Edition. London: Pearson.
- Martin F and Thompson M (2010) *Social Enterprise: Developing Sustainable Businesses*. Basingstoke: Palgrave Macmillan.
- McGrail M, Stirling R, Humphreys J and Ward B (2015) Accessing doctors at times of need—measuring the distance tolerance of rural residents for health-related travel. *BMC Health Services Research* 15(1): 212.
- Radcliffe J (2011) Email Communication. World Health Organisation.

- Ridley-Duff R and Bull M (2011) *Understanding Social Enterprise: theory and practice*. London: Sage.
- Ridley-Duff R and Bull M (2016) *Understanding Social Enterprise: theory and practice*. 2nd Edition. London: Sage.
- Schumpeter J A (1934) *The Theory of Economic Development*. Cambridge, MA; Harvard University Press.
- Scott J and Marshall G (2005) *Oxford Dictionary of Sociology*. 3rd Edition. New York: Oxford University Press.
- Seanor P, Bull M, Baines S and Ridley-Duff R (2013) Narratives of transition from social to enterprise: you can't get there from here! *International Journal of Entrepreneurial Behaviour and Research* 19(3):324-343.
- Sklenarova H, Krümpelmann A, Haun M, Friederich H, Huber J, Thomas M, Winker EC, Herzog W, and Hartmann M (2015) When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer* 121, No. 9: 1513-1519.
- StatsWales (2018) Population density (persons per square kilometre) by local authority and year. <https://statswales.gov.wales/Catalogue/Population-and-Migration/Population/Density/populationdensity-by-localauthority-year> (Last Accessed 25th July 2018).
- The Stroke Association (2016) The State of the Nation 2016 - Stroke Statistics Report. https://www.stroke.org.uk/sites/default/files/state_of_the_nation_2016_110116_0.pdf (Last Accessed 24th December 2016).
- US Census Bureau (2007) Questions and Answers Centre ID623. Definition: Urban and rural. <http://ask.census.gov> (Last Accessed 4th April 2012).
- Wengraf T (2009) *Qualitative Research Interviewing: Biographic Narrative and Semi-structured Methods*, New Delhi: Sage.
- Welsh Government (2014) Social Services Wellbeing Act. [Http://www.legislation.gov.uk/anaw/2014/4/pdfs/anaw_20140004_en.pdf](http://www.legislation.gov.uk/anaw/2014/4/pdfs/anaw_20140004_en.pdf) (Last Accessed 15th February 2017).
- Welsh Government (2016) Together for health: Stroke Annual Report 2016. <http://gov.wales/docs/dhss/publications/161128stroke-reporten.pdf> (Last Accessed 15th February 2017).
- Welsh Government (2017) Stroke Delivery Plan 2017-2020. [Http://gov.wales/docs/dhss/publications/170209stroke-dplan1720en.pdf](http://gov.wales/docs/dhss/publications/170209stroke-dplan1720en.pdf) (Last Accessed 15th February 2017).
- White CL, Barrientos R, and Dunn K (2014), Dimensions of uncertainty after stroke: perspectives of the stroke survivor and family caregiver. *The Journal of neuroscience nursing: journal of the American Association of Neuroscience Nurses* 46, No.4: 233-240.
- Williams C (2008) *Social Policy for Social Welfare Practice in a Devolved Wales*. UK: British Association of Social Workers.