



# The meaning of loneliness to stroke survivors: A qualitative study in Northeast England

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## Abstract

This study explored stroke survivors' experiences of loneliness. Drawing on interviews with 29 community-dwelling stroke survivors living in the Northeast of England, we found several themes: loneliness as being alone, the season or time, lack of understanding from those without any experience of stroke, reduced autonomy, and deterioration of social relations. It is important that healthcare professionals pay attention to the aspects of life that may increase the chances of a stroke survivor becoming lonely after being discharged from hospital, and to measure loneliness in stroke survivors a more valid scale should include items that touch on the aspects reported here.

## Keywords

loneliness, qualitative methods, social isolation, stigma, stroke

## Introduction

According to the UK's National Institute for Health and Care Excellence (NICE, 2019), stroke is the biggest threat to public health, with more than 100,000 strokes annually in the UK. Not only does this result in 38,000 deaths, but the majority of survivors are discharged from hospital with a disability, and the cost of care is estimated at £25 billion per year. The future looks no less bleak, with stroke survivor numbers expected to rise by 123% from 2018 to 2035 (Stroke Association, 2017).

The most widely cited definition of loneliness does not describe the nature of loneliness but explains it as a result of "the lack of desired social relations" (Peplau and Perlman, 1982). Loneliness has also been increasingly identified

as a serious public health issue (Gerst-Emerson and Jayawardhana, 2015). Some researchers identified a series of risk factors for loneliness for different age groups (Hawkey et al., 2019; Luhmann and Hawkey, 2016; Victor and Yang, 2012; Yang and Victor, 2011), whilst others have examined the connections between loneliness and specific conditions such as cancer

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(Mosher et al., 2012), cardiovascular diseases (Everson-Rose and Lewis, 2005; Hawkey and Cacioppo, 2010), dementia (Prieto-Flores et al., 2011), depression (Cacioppo et al., 2010) or chronic illness in general (Maguire et al., 2019).

Nevertheless, the relationship between stroke and loneliness remains unspecified. Stroke is different from other cardiovascular diseases in terms of aetiologies, symptoms, and effects on health. Some studies have measured loneliness as a key predictor of cardiovascular diseases in general or some conflation of stroke with other diseases (Christiansen et al., 2016). However, conclusions drawn from analyses on other cardiovascular diseases may not be applicable to stroke and its relationship with loneliness.

There is good reason to expect a connection between stroke and loneliness—45% of stroke survivors report feeling “abandoned” upon hospital discharge, with a third experiencing post-stroke depression (Stroke Association, 2016). However, identifying causal connections between the two is challenging. Most previous studies have explored loneliness as a risk factor (Holt-Lunstad and Smith, 2016), but it is important to consider that loneliness and stroke could form an interactive causal sequence: loneliness triggers the first incidence of stroke, which then increases the frequency or severity of the patient’s loneliness, and the worsened loneliness will in turn lead to exacerbated symptoms, poorer recovery or another stroke, leading to increased loneliness. The cycle could of course also begin with stroke. Although any particular study may concentrate on only one part of the chain, researchers should keep the overall loop in mind. Strokes can impair global cognitive function, immediate and delayed verbal memory, semantic verbal fluency, and processing speed (Llewellyn et al., 2008). Since these all relate to communication abilities, impairment of these functions is a probable cause of loneliness, which in turn may hinder recovery. Such relatively longer causal connections were found in some samples (Warner and Kelley-Moore, 2012), although the sequelae could be other forms of psychological suffering, such as depression (Huang et al., 2010) or distress (Hilari et al., 2010), which are associated with loneliness.

The causal relationship between stroke and loneliness is complicated further when other contextual factors are considered, such as social support and socio-demographic attributes. Petitte et al. (2015) retrieved 10 quantitative studies of stroke survivors with appropriate measures of both loneliness and stroke, discovering that loneliness, post-stroke depression, stroke occurrence, and poor post-stroke recovery were linked. This is particularly the case for stroke survivors living alone after stroke, who account for one quarter of all stroke survivors in England, Wales, and Northern Ireland (Stroke Association, 2017).

Furthermore, it is a major challenge to effectively capture the sense of loneliness among people with chronic illnesses by using existing psychological scales. Existing studies of loneliness usually target the general adult population or older people, the majority of whom were not suffering from a serious illness at the point of data collection. Psychological scales developed for measuring loneliness have not been designed for subjects with any chronic or severe illness. It is therefore likely that they may not be completely valid with respect to representing the features of loneliness that are idiosyncratic to this special group. As such, an important benefit of this qualitative study is that stroke survivors’ narratives could shed light on how best to capture post-stroke loneliness more precisely.

This study aims to explore and discover the meaning of loneliness specific to stroke survivors in Northeast England. This region has a relatively higher prevalence of social deprivation than other regions of England (Corris et al., 2020), and social deprivation has been found to increase stroke risk (Stroke Association, 2017). Such understanding will help reveal potential causes or triggers of loneliness, which could include not only stroke itself and subsequent impairments, but also other social and psychological problems such as living alone, social isolation, stigma, or even unexpected issues such as the “seasonal adjustment disorder.” Only by knowing these factors can they be tackled effectively and thereby loneliness reduced. In addition, our study aims to recommend ways to develop a customised scale for measuring loneliness among stroke survivors.

## Data and methods

The project was conducted in accordance with the Declaration of Helsinki and received approval from ethics committees at our respective universities.

We recruited stroke survivors via local charity stroke groups and our existing contacts. The study eligibility criteria included the following: being an adult (aged above 18 years), living in the Northeast of England, and having had at least one stroke in the past. In the end, 30 participants were recruited, but one interview was excluded from the analysis as the respondent did not comment upon loneliness during their interview. Semi-structured interviews were conducted face-to-face between March and September 2019. We offered £10 and a notebook souvenir to each participant as a token of our gratitude for their time. All interviewees (13 females, 16 males; 25–81 years old; mean age: 61.9) were British and resided in the Northeast of England. Our observations of the interviewees' properties and living conditions during interviews led us to believe they were from diverse socio-economic backgrounds. Further participant demographics can be found in Supplemental Material A.

All interviews took place in the interviewees' own homes, except one who chose to be interviewed at a university. For some interviews it was unavoidable that a carer of the interviewee (e.g., spouse, sibling) participated in the interview. Interviews, typically lasting about one hour ( $M=65.19$ ;  $SD=24.30$ ), were recorded with consent and later transcribed by a professional agent.

Following "the framework method" (Gale et al., 2013), each transcript was anonymized and read by two researchers, and their coded texts were compared and summarised for further interpretation. A small number of editorial corrections were made to transcripts to make them more readable.

**Data Sharing Statement:** The current article includes the complete raw data-set collected in the study including the participants' attributes, interview transcripts (with potentially identifying details redacted), descriptive results, and a

memo of data analysis. Pending acceptance for publication, all of the data files will be automatically uploaded to the Figshare repository. Full project data and materials can be found on the Open Science Framework.

## Key themes and findings

Descriptive statistics of the loneliness measures demonstrating the extent of the interviewees' loneliness can be found in Supplemental Material B.

### *Loneliness is being alone for a long time*

To many of our participants, "defining by explaining" seems a natural way of talking about loneliness. Rather than describing the subjective state of *how they feel* when lonely, they describe *objective events or states* responsible for their feelings. When asked to define "loneliness," many of our interviewees thought about being alone. As a 71 year old married man (M16) said:

"I think it's probably the worst thing in the world, it's being on your own and not having contact with people, it's really hard."

Others emphasized the length of the "aleness" ("a long time," "for hours on end," etc.). The aleness will become unbearable ("the worst thing") once it reaches a certain length of time, with the length of time varying considerably from person to person, depending on one's ability to be alone without suffering mentally; however, it will soon reach its limit if no one comes to offer the much-needed interactions ("having nobody to bounce off," "no one comes around").

### *Loneliness comes in winter, long dark nights, and weekends*

Some stroke survivors felt particularly lonely during the night or winter, and one interviewee mentioned "weekend" as well. A 63 year old widowed man (M04) explained why:

“I feel lonely at night. . . loneliness is being alone, really alone, like at night. . . . I’ve felt lonely every night. Nights are the worst time.”

A 49 year old single man (M08) realised that his loneliness could be a symptom of Seasonal Adjustment Disorder, a form of depression at a particular time of year:

“Very isolated, pure and simple, especially during the winter. . . I found it was very, very difficult because it was just long, dark nights . . . even though you have got all the people phoning you, texting you. . . , this Seasonal Adjustment Disorder”

### *Loss of independence, lack of understanding, and protection of self-image*

Only a minority of stroke survivors recover completely; others will realize the painful new reality that they can no longer do something they used to do. Many participants particularly lamented the loss of “independence” or “freedom” after stroke; a 63 year old married man (M02) gave a typical illustration:

“Just the fact that you can’t go anywhere you know. . . it’s the lack of independence because of the driving. That causes you to feel sort of lonely in not being able to go anywhere and do stuff you wanted to do really.”

A 50-year old divorced woman (F07) explained how loneliness before her stroke was different from the loneliness due to the stroke:

“Before I was poorly you could be lonely because . . . I had not gone out so that is your choice . . . . Whereas when you are poorly it is not a choice. . . you are forced into a loneliness that you can’t get out of, so . . . you get into a bit of a spiral of depression, that kind of version of loneliness.”

The loss of independence is more than losing a particular ability; it is also a psychological blow because the loss can make stroke survivors see themselves differently. The new but unfavourable

self-image—the previously capable, free, and outgoing me is no more—compounded by reduced opportunities to interact with others socially, appears to be a key source of loneliness among stroke survivors.

Most stroke survivors keep the less favourable image to themselves, making it difficult for others to understand what they went through. This reluctance of sharing their feelings with others combined with the lack of efforts made by others to understand them puts up “a mental wall,” leaving the stroke survivor lonely. “Never share anything negative about yourself with others” is a social norm they adhere to. In such a situation, the presence of others is not only unhelpful but actually responsible for the stroke survivor’s loneliness. A 43 year old married woman (F03) offered an explanation that some others shared:

“I can still be with people but feel lonely because I’m not the same as them. Like they can be doing things that I can’t, and that makes me feel lonely. . . . even playing sports and stuff because the eye co-ordination [is] not there. . . .”

Why would stroke survivors not tell others how they feel? A few stroke survivors explained to us that they would not take the risk of displaying their vulnerabilities. To protect their self-pride or dignity, they hoped the others could understand them without being asked to do so. As a 63 year old married man (M03) confessed to us:

“Well, pride’s a sin. But I’m a bit too proud sometimes just to say that I’m lonely.”

Other interviewees followed the same principle of only letting others see “a positive you”: when talking to others, they would “put on a brave face,” “smile,” or “tell people I am OK all the time.” A 68 year old widow (F04) elaborated on this point:

“And when people ask how I am, you all say fine, don’t you? . . . It’s a typical British thing, isn’t it? . . . if I feel down or lonely, I’d never get in touch with you. It’s when I feel alright, then I’ll phone you. . . .”

As a result, stroke survivors are caught in a conundrum: they have a desire for others to understand their feelings, but at the same time, their desire to protect their self-image makes it more difficult to achieve such understanding.

### *Stigma prevents stroke survivors seeking help*

To protect one's dignity, people essentially self-stigmatise loneliness as they believe that others hold a negative view of loneliness, even though such belief may be unfounded. Stroke survivors would rather assume the existence of the stigma than to find out whether others do hold the view. A single man of forty-nine (M08) emphasized that the stigma was more common among the older generation:

“There is a stigma with regard to anything to do with loneliness and mental health . . . to the older generation that stigma is still there . . . you are supposed to just suck it up and get on with it.”

Other interviewees did not mention the word “stigma,” but were clearly concerned with the negative views others would have if they asked for help. A married woman (F03) was frank when she told us:

“I worry more about what other people think than what I'm actually feeling.”

Another, much older, woman also told us she found it “very hard to ask for help.” A 63 year old divorced man (M12) confessed the same reluctance:

“I always find it awkward if I ask people for help. . . . Within meself, I can't bring meself for asking for help.”

Rather than voluntarily telling others they need help, they would wait for others to ask. Even when others did, they may not tell the truth because it would also depend on *how* they asked. To stroke survivors, stigma means not only the embarrassment of acknowledging one's vulnerability to others, but also the low

probability of obtaining genuine sincerity from others.

### *Stroke, social relations, and loneliness*

How those around stroke survivors treat them played a significant role in their mental state. To stroke survivors, any loss of independence means increased dependence on others, which they may interpret as being burdensome or a nuisance, even if that may not be what others believe. Understandably, they became much more sensitive to the way in which others treat them after stroke. Of all the stroke survivors we interviewed, those who had a caring spouse were the least likely to become lonely. Nevertheless, marriage, family, or living with a partner itself is no guarantee of keeping loneliness at bay. A 73 year old woman (F13) was married, living with her husband and had an adult son. Unfortunately, she could not count on either of the two men:

“And to ask my son for anything, haven't got time. . . . I am invisible, honestly, because people don't see us. . . . It takes us all his [her husband's] time to talk to me about anything. . . he just sits there all day and watches telly all day.”

Compared with her, the 71 year old married man (M16) was in a somehow luckier position—he was happy with how his wife looked after him but complaining about the lack of contact from his sons and sister:

“. . . why don't the boys [his sons] come and see me? . . . we have done everything for them and now we feel as if we are abandoned . . . , I think they should be a little bit more appreciative of us . . . Now I have never spoken to my sister, . . . why should I [if] they don't ring me?”

This expectation of contacts or increased sensitivity to any subtleties in how others interact with them extends beyond family, which is clearly connected to the previously mentioned lack of understanding from others. Having a stroke seems to have either raised what they would expect from others or made them more

sensitive to the social relations that they perceived as normal before having a stroke. A few other survivors had similar issues with the lack of contacts from their former colleagues and friends.

Beyond family and close relations, being with a number of others is no guarantee of staying away from loneliness. A number of our interviewees experienced this kind of “loneliness among others,” of which a 50-year-old divorcee (F07) gave an explanation and illustration:

“Maybe it is like an isolation loneliness because you have had a stroke you can be lonely in a big group of people. . . . You can be in a group and think ‘why am I [in] this group because no one is discussing anything’ and it is like I could just be at home and lonely on my own.”

Later she gave an example of such a situation, when others did not think, or at least as she believed, that she was not clever enough to understand what they were saying or was able to “put my foot in it and everyone would laugh.” Some stroke survivors may find it difficult to fit in an existing social circle, and readily resort to their stroke to explain the social isolation they experienced.

## Discussion

We started this study with the aim to understand how stroke survivors experience loneliness, and whether existing academic definitions accurately capture these experiences. The following section reflects on what they shared with us, what their experiences mean for developing a new scale on loneliness, and discusses the study’s limitations.

### *What we have learnt about loneliness from stroke survivors*

Participants frequently referred to the word “alone” when defining loneliness. Whilst loneliness researchers have repeatedly warned against using aloneness and loneliness interchangeably (Victor et al., 2000; Yang, 2019),

stroke survivors cannot help but doing so. How could we account for the disparity between academic and lay approaches to defining loneliness with aloneness? For academic research, it is imperative to draw clear and indisputable boundaries between concepts even when they are tightly associated. In contrast, stroke survivors think from their direct experiences. Being alone does not necessarily bring about loneliness. Despite this, it was the image of being alone that came to stroke survivors’ minds when thinking about the meaning of loneliness; it seems hard for stroke survivors to describe a mental state without referring to a related physical state.

Based on the data above the meaning of aloneness to the stroke survivors is different to the healthy adult population. If aloneness does *not necessarily* lead to loneliness, then can we identify the conditions under which it does? One mechanism for this specifically to stroke is that stroke survivors were conscious of the relatively new but disheartening fact that their abilities to prevent being alone from developing into loneliness had been seriously compromised; when alone, healthy adults are also vulnerable to loneliness, but they are much more resourceful and capable of minimizing the likely transition from aloneness to loneliness. Either partial or complete loss of cognitive or physical abilities can mean immobility, difficulties in communication with others, and reduced contents of one’s life so that daily life remains manageable. If so, being alone at home seems almost inevitable. Aloneness among stroke survivors offers a quintessential example of “imposed aloneness” (Diekema, 1992; Yang, 2019), which has a much higher chance of turning aloneness from a necessary to a sufficient condition for loneliness. It is not difficult to imagine that when being alone is not one’s choice, one is almost certainly to feel powerless or hopeless. Circumstantial factors such as a long, dark, and cold night in an empty and quiet house, would bring a feeling about a physical setting closer to a mental state. Clearly it is not night-time or winter-time *per se* that made them lonely, but the cold, dark circumstances may prevent one

from joining others and provide a legitimate reason to others for not visiting.

In contrast to such “physical aloneness,” which will enhance the probability of loneliness, stroke survivors also experienced what we may call “identity aloneness,” that is, the awareness of how different they are from who they were before, and from those around them (Kitzmuller and Asplund, 2018). Whether and how they modify their previous identity depends on how people around them treat them differently, which will in turn affect their self-esteem and sense of loneliness (Tian, 2014). Whilst any identity can separate anybody apart from others, stroke survivors were especially wary of the possible undesirable labels either they themselves or others put on them. This is why they cared and worried about losing their independence, or taking on a new identity of “the dependent,” or “the sick one.” Even if they could accept their “new you,” they found it a daunting task to make others understand this “new you” without putting a negative label to it.

To be different from others is not necessarily an issue, but to be different from others with an undesirable label is, and such difference is an important source of loneliness. Should we use the most widely adopted definition of loneliness (Perlman and Peplau, 1982) [AQ: 1] to understand the loneliness among the stroke survivors, we must be specific about what kind of “desirable social relations” are missing in their life. Stroke survivors found it an unpleasant surprise that they had to make new effort to protect their identities because their social relations had somehow changed due to the stroke. If it is not realistic to expect all those around them to be very understanding and caring, then it is inevitable that some stroke survivors will feel lonely. Our interviewees did hope to have social relationships in which they did not feel their identity was perceived as socially undesirable, and this is something that at least some of the respondents felt could be achieved by attending stroke support groups and meeting others who had some shared experiences.

One identified issue in stroke survivor responses was rather than seeking help they would wait for help to be offered. Reinforcing previous

findings regarding perceived stigma being associated with poorer help-seeking attitudes (Corrigan et al., 2014; Pepin et al., 2009). Stroke survivors also explained this in terms of the low probability of receiving genuine and sincere help. Stroke survivors’ unique profile as individuals likely living with a multi-morbidity disorder, coupled with the issues identified above, places them in a more disadvantageous position with a higher rate of identified barriers to seeking help, further increasing their likelihood for isolation.

In its simplest form, peer support can be defined as being composed of individuals who share a similar problem and come together to provide mutual help and support (Adamsen, 2002). With the post-stroke change in personal identity and the stigma and help-seeking issues, many stroke survivors recognised peer support groups as a safe space. Peer support provides a space to self-disclose, the opportunity to be accepted and to share information (Evans, 2011). In this way, peer support groups provide a coping strategy for dealing with loneliness for many of the stroke survivors we interviewed.

In addition to usual physical rehabilitation, this study has shown the need for “identity rehabilitation” by sharing experience with peer support, which could provide tools for self-empowerment to avoid the loneliness sequence. Health and social care institutions would do well to utilise and value these support groups; at least some stroke survivors may find them beneficial for addressing loneliness.

### *Suggestions for scale construction*

Currently, loneliness is measured with either a single question or a scale of multiple questions. Large scale social surveys tend to use a single question to minimise the responding burden. When reliability is of great concern, researchers prefer a scale with multiple questions, and the most widely established is the UCLA 3-item scale (Hughes et al., 2004). To measure loneliness in a more balanced manner, de Jong Gierveld and van Tilburg (2006) developed a 6-item scale which measures both emotional and social loneliness.



Whilst these measures are useful for capturing some “universal” features of loneliness, they do not relate to the specific experiences of stroke survivors. Therefore, a new scale particularly for stroke survivors may help to measure their experiences of loneliness more accurately, therefore resulting in increased detection and hopefully the ability to intervene where required.

The data presented here suggests that such a new scale should address identity and survivors’ communication with others. Firstly, how the stroke survivor sees themselves since the stroke. With companions around them and involving them, stroke survivors would not feel isolated, at least not in the sense of the three items of the UCLA loneliness scale, but they may still feel lonely. To reflect their sense of loneliness more precisely, a new loneliness scale should therefore contain items about how they identify themselves; for example, whether they can continue to do things they used to do, and how much independence they have lost since the stroke. Additionally, a new scale should capture stroke survivors’ communication with others. Except for a few occasions when they can share their experiences and feelings with other stroke survivors (for example in designated support group situations (Ketokivi, 2009)), they are surrounded by people who have not had a stroke, already setting them apart from others. As a result, they become sensitive to whether others understand their feelings, or at least the intention to do so. Other people’s understanding carries even more weight if stroke survivors’ abilities to communicate, particularly speech and cognitive functions, have been impaired. It is therefore imperative for a new scale to include items that cover both the perception of understanding by others, and the stroke survivor’s confidence expressing themselves in front of others.

### **Limitations**

The stroke survivors in our study should not be taken as a representative sample of stroke survivors in the Northeast, let alone the UK. They were recruited from research associations and local stroke charities and groups. As such, the

views and circumstances of these stroke survivors might be different from those survivors who, for example, did not belong to any association.

Additionally, the time since stroke across participants was variable, with some participants suffering their stroke a few years and for others in the year of the interview. As such, participants with greater time since their stroke may have adapted to their new level of functioning, and may have potentially been able to return to personally valued activities (Ch’Ng et al., 2008; McKevitt, et al., 2004). Therefore, participants with greater post-stroke adaptation may have reduced loneliness, or more effective ways of managing their isolation.

Some carers were present during the interview, helping participants recall or communicate information. Although their presence was positive in some respects, this may also have hindered participants from providing honest responses.

Our recruitment strategy for this project was to generate a participant pool that was representative of stroke survivors generally, rather than one facet of stroke (e.g. age, gender, specific comorbidity, time since stroke, etc.). In this way the data provides a holistic representation of the views of stroke survivors rather than a specific sub-group within this population. It would be interesting to understand if specific differences in experience do exist between such sub-groups, and therefore future projects could look to explore this.

### **Conclusion**

Impairment of some physical or cognitive abilities is an almost inevitable consequence of stroke, with existing care tending to prioritise physical recovery. This study highlights the importance of paying serious attention to wider psychological impacts of stroke such as loneliness, which if left untreated could lead to additional medical conditions or exacerbate comorbid symptoms. Although loneliness among stroke survivors shares certain common features with loneliness among other adult groups, such as the desire for understanding from those around them, this study has revealed a few important

meanings that appear more distinct to stroke survivors. Particularly their desire to maintain their pre-stroke identity, dignity, and independence. To minimize their chance of experiencing a vicious cycle of loneliness and new episodes of stroke, those who are in relations with or caring for stroke patients must consider how stroke survivors see themselves and their changing social relations. We hope other researchers would join us to incorporate these newly discovered aspects of loneliness in future studies of larger scale. Future research will benefit from creating and employing a scale of loneliness customized for stroke survivors, which should incorporate items on self-identity and social relation perceptions.


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### Supplemental material

Supplemental material for this article is available online. [AQ: 7]

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