Introduction

Stroke is the primary cause of disability in England (National Audit Office, 2010) and leads to reduced physical activity and cardiorespiratory fitness which, in turn, are associated with increased cardiovascular risk (Ivey et al., 2005). Following stroke, patients are at risk of recurrent stroke (approximately 25% within five years) and other vascular events (Redfern, McKevitt and Wolfe, 2006). Risk factors that lead to recurrent vascular events include lifestyle risks such as poor diet, obesity, lack of exercise and smoking (Lawrence et al., 2009).

Previous qualitative research exploring perceptions towards healthy living in people with stroke has been mainly focussed on the identification of barriers and facilitators to exercise post stroke. Nicholson et al (2012) conducted a systematic review of five qualitative and one quantitative study that explored barriers and facilitators to exercise. Four of the studies were conducted in the USA, one in Australia and one in the UK. The authors concluded that lack of motivation, environmental factors and stroke impairments were the main barriers to engaging in exercise post stroke, and that the main motivators were the desire to return to independence and support from family and professionals. One further study in Canada (Simpson and Eng, 2011) found similar results and stated the main barrier for patients with chronic stroke was self-efficacy. This study and the systematic review mainly focused on patients with chronic stroke. It is debateable whether barriers and facilitators to exercise will be the same at all stages of post-stroke recovery and with different levels of stroke severity. The present study, therefore, aimed to focus on perceptions of healthy living of patients with sub-acute, mild to moderate stroke rather than a discussion of barriers and facilitators to exercise.

Previous research exploring the understanding of healthy lifestyles of people with stroke has focussed mainly on the provision and delivery of advice. A survey of people with stroke conducted by the Healthcare Commission (2006) found that 43% of respondents were not given any information about dietary changes and one in three were not given any information about physical exercise. In the same year the Stroke Association (2006) conducted an audit of stroke units and patients and found that only 46% of patients were given any information about future stroke prevention. The American Stroke Association (2006) recommended cardiovascular training and lifestyle modification to reduce the risk of further stroke.

A Cochrane review exploring information provision for stroke patients and their caregivers (Forster et al., 2012) found that active information provision, where the participants were able to ask questions and relate the information to their experience, was more successful than a passive approach in improving knowledge. The review aimed to assess the effectiveness of information provision strategies for stroke patients and their caregivers, however, all the studies in the review measured knowledge using a variety of structured questionnaires and no qualitative studies were identified. Assessment of knowledge was a component of the design of all of the studies in the review and as Hillsdon et al (2013) commented ‘future research should explore views of people not included in a trial’ (Hillsdon, Kersten and Kirk, 2013:7). Therefore, the aim of the present study was to explore the perceptions of healthy lifestyles in individuals following a sub-acute stroke who were not involved in other studies.
Methods

A qualitative phenomenological approach (Dowling, 2005) was chosen as most appropriate to gain an in-depth understanding of individuals’ perceptions of the topic of interest.

Ethics

Prior to recruitment and data collection, ethical approval was gained from the Northampton Ethics Committee (Reference: 14/EM/1067). Anonymity and confidentiality were ensured and informed consent obtained from all participants.

Participants

Twenty participants with a range of sub-acute, mild to moderate stroke were recruited from stroke units, early supportive discharge teams, community teams and TIA clinics at a large University teaching hospital. Participants were purposively chosen if they had had a mild to moderate stroke (using NIHSS scale, mild < 6, moderate 6 - 15) (National Institute for Health, 2016) or TIA, were within six months of their stroke and could walk 10 metres. Seven of the participants had carers present who contributed to the discussions.

Procedure

An interview schedule (Table 1) was developed by the Principal Investigator (NCB) and research team, and was piloted with a patient representative who met the broad inclusion criteria, and his carer. The pilot interview offered the opportunity to refine the questions and enhance the principal investigator’s (PI) qualitative interviewing skills. Thereafter, semi-structured in-depth interviews, approximately 45-90 minutes in length, were conducted with 20 participants’ in their homes. In seven of the interviews the carers were present, however, the questions were primarily directed to the individuals with stroke during the interviews. The carers were involved at the participants’ request and their comments were audiotaped and probing questions asked as necessary.

Fourteen interviews were conducted by the PI and six by research assistants (AH and SD), who had previously received guidance in qualitative interviewing from the PI. Field notes were written after each interview, recording details, such as, the participant’s level of disability, home environment, body language and other observations. Data collection, and the initial stages of data analysis, occurred concurrently and the interviews were continued until it was considered that data saturation had been achieved. All interviews were audiotaped and transcribed verbatim by a professional transcriber. The participants were offered the opportunity to review their interview transcripts in order to add or delete content if they wished, however only two participants chose to be involved at this stage.

Table 1.

Data analysis

Thematic analysis was conducted according to the analytic framework developed by Braun and Clarke (2006). The data were analysed by the PI (NCB) and a colleague (CC) with experience in qualitative approaches, and the research assistants contributed additional
insights. Open inductive coding through line-by-line reading of the transcripts of participant interviews was undertaken. In each transcript participants’ statements that appeared to inform the study purpose, were highlighted and codes assigned that represented the key message or concept of these statements. The coded data were gradually abstracted from the transcript and condensed until a number of core categories were identified that provided an in-depth description of participants’ perceptions of healthy lifestyles. These core categories were then used to develop key messages.

The PI (NCB) consistently reflected on how her own personal and professional assumptions and beliefs about exercise and maintaining a healthy lifestyle could influence the data collection and analysis processes. She has been a neurological physiotherapist and university lecturer for 26 years. She made every effort throughout the study implementation to make explicit her positive attitudes towards exercise and the importance of healthy living. During the interview process she did not identify herself as a physiotherapist in case that knowledge influenced the participants’ responses. One research assistant, who was less positive of the benefits of exercise post-stroke, was specifically asked to contribute to the analytic process.

Results

Twenty volunteers participated in the study, 12 men and eight women who ranged in age between 30 and 88 years. Their ethnicity reflected the local population, with 14 Caucasian, four Asian and two Afro-Caribbean participants. The average length of time post stroke was 59 days (range 14 – 124) (see Table 2: Participant profile). In seven interviews participants’ carers were present and contributed to the discussion.

Table 2.

Data analysis identified three core themes: Perceptions related to exercise, Perceptions related to other lifestyle factors and Understanding of stroke and healthy lifestyles.

Perceptions related to exercise

Sub-categories contributing to perceptions related to exercise were: Activity or Exercise, Benefits of Exercise, Motivators and Difficulties

Activity or exercise.

Most participants were active prior to their stroke. Some stated that they were very active at work or getting to and from work, or around the home doing housework or working in the garden. Some participants engaged in more formal exercise regimes or sporting activities:

*I play bowls a lot...that keeps me very active as regards sport because I like sport* (P12)
However, when the frequency, time and intensity of exercise were discussed only five participants appeared to be achieving the recommended level of cardiovascular training of 150 minutes a week at a moderate intensity (World Health Organisation, 2011). Some were achieving the duration required but not the intensity.

Benefits of activity

Participants identified a number of benefits of activity such as social benefits: “we just went for the social aspect of it” (P1), psychological benefits: “I think it gives you a positive outlook” (P2) and physical benefits such as weight control: “I joined the gym about 10 weeks before I had the stroke and I’d lost about three quarters of a stone...I looked at it that I’m going to lose weight and that’s it.” (P14)

Being independent was clearly very important to the participants and associated with ‘getting stronger,’ and ‘doing exercise’. As one participant said “it [exercise] helps you to become a bit more independent” (P1). The participants functioned independently before having a stroke and were keen to achieve independence again. As one carer said: “because she [P20] was very independent before it, she feels bad that somebody has to give her a shower or bath.” (P20). This desire for independence also linked with an overwhelming need to be ‘normal’ again. Exercise was seen as a way to achieving normality:

_It will make me feel normal again, the more I can do the more I feel I am just back to normal and it’s gone away._ (P13)

However, the participants did not identify the benefits of reducing their cardiovascular risk factors such as decreasing blood pressure and cholesterol levels or the relationship of these with a decreased risk of future cardiovascular events. The link between exercise and risk prevention or reduction were clearly not understood by the participants.

Motivators

Participants identified a number of factors they felt would motivate or facilitate their involvement with exercise post stroke. Using Social – Cognitive Theory (Bandura, 2004) facilitators of exercise engagement can be divided into personal, social and environmental. The personal facilitators the participators in this study identified included: the fear of having another stroke, the fear of being dependent, religious guidance, and enjoy being competitive. In other words, participants did not “want to be beaten by the stroke” (P13). The social facilitators of exercise included: religious beliefs, support from friends and families, walking groups and support from therapists and exercise professionals. The personal and social facilitators identified in the literature highlight the importance people with chronic stroke attribute to the support of family, friends and professionals in encouraging them to establish and achieve their exercise goals. The participants in this study did not identify any environmental facilitators that might encourage them to exercise post stroke.

Difficulties
A number of difficulties or barriers were identified related to exercise post stroke. Personal difficulties associated with exercising included pain, fear or experience of falling, and fatigue. A number of participants identified pain and the existence of multi-pathologies as difficulties to exercise post stroke:

- "I used to be very active before the arthritis started taking over...I get a lot of pain in my back it’s putting the mockers on it a bit." (P1).

The participants identified fear of falling and having a fall as factors preventing them from participating in exercise, in particular, because their confidence was undermined and the experience of falling was difficult to overcome. As with the general falls population (Jung et al, 2009), participants’ fear of falling was not necessarily associated with having fallen. As one participant explained: “The negativity is constantly thinking I might fall” (P3). Some participants’ commented that other peoples’ attitudes contributed to their fear of falling: for example, one participant pointed out that “it’s the blame culture, if I fall over then it will be them (the nurses) that’s blamed not me” (P2) or one carer said: “I don’t let her walk on her own because she’s had a couple of falls” (P20).

Participants also identified fatigue as a personal difficulty to participating in exercise post stroke. Fatigue in long-term conditions has been described as “decreased mental and physical endurance” (Krupp, 2003: 12). As one participant explained “it is an overwhelming problem that is constant - I am always tired” (P9) and “it’s not that I want to go to sleep, it’s my body says it wants to have a rest” (P16). This problem has also been identified in the literature in relation to the chronic stroke population (Forster et al, 2012). Interestingly, in the Chronic Fatigue population (White et al, 2011), exercise has been shown to improve fatigue for people with chronic fatigue, however, this was not something that the participants in this study identified or discussed.

A number of participants expressed concerns about ‘overdoing it’: “Yes my main concern is it’s going to be a sudden shock to the system to all of a sudden be bouncing around” (P3) and “I think you can take exercise to the extreme” (P11). This perhaps highlights a lack of knowledge and understanding of appropriate exercise programs and progression and the potential risks of exercise. Other personal difficulties included a degree of embarrassment associated with the physical aspects of stroke: “You’re embarrassed to be like this” (P14). Interestingly, a lack of motivation were not identified as difficulties to exercise post stroke.

Only one social difficulty to exercise after a stroke was identified in the interviews. For one participant (P7) religion was a barrier to exercise as she was unable to exercise with a mixed gender group and with male instructors. In the local area this issue has been addressed with some facilities providing female only group swimming with female lifeguards. However, many exercise facilities do not offer these options.

Finally, a number of environmental difficulties were discussed including inadequate or lack of accessible transportation. “Well the first obstacle is how do I get there and back” (P10). This participant lived in the countryside without public transportation although others lived
in the city and still had problems; for example, “The problem is the gym is the other side of town” (P3).

Some participants were constrained by insufficient finances: “Financially it’s [living with a stroke] crippled me” (P3) and “I think the only thing that worries me...is that I am always worrying about money” (P9). These difficulties have previously been identified in research with people in the chronic stage of stroke recovery (Nicholson et al, 2012) and identify the need to provide facilities that support people who have had a stroke to exercise in the long term.

Perceptions related to Other Lifestyle factors

Sub-categories contributing to Perceptions related to Lifestyle changes were: Changes to Lifestyle and Doubts and disagreements.

Changes to lifestyle

Most of the participants wanted to achieve a healthy lifestyle by improving their diet after the stroke: for example, “Cut down on the eating and start doing more exercise.” (P3), or stopping smoking: “No I stopped it, after this, completely I have stopped.” (P7), or losing weight: “I could do with losing 2 or 3 stone.” (P11). Although they were unable to articulate any definite plans or details about how they were going to instigate this lifestyle change or maintain the change. The participants recognised the importance of changing their lifestyles in order to improve and maintain their health but they did not appear to have the information necessary to support these changes.

Doubts and disagreement

Some participants expressed doubts about the positive benefits of a healthy lifestyle as despite their belief that they had lived a healthy lifestyle they still had the stroke or they cited other people they knew, who they believed were healthy but who still had a developed significant health problems: “I know people who exercise regularly have had heart attacks as well” (P1) and “When you think that the guy who started jogging died jogging apparently...he had a heart attack” (P9). “My wife died of lung cancer and she stayed in a ward and everyone on that ward had lung cancer and only one smoked” (P11). “I did a lot of exercise and it didn’t do me any good” (P19). These perceptions could be interpreted as examples of confirmation bias (Nickerson, 1998) defined as “seeking or interpreting of evidence in ways that are partial to existing beliefs, expectations, or a hypothesis in hand” (Nickerson, 1998: 175). It indicates that behaviour change for some participants might be difficult if they tend to select negative messages or even disagree with the concepts of benefits and risks and the preventative advantages associated with maintaining a healthy lifestyle, for example, “are you trying to tell me having low cholesterol is a good things – I don’t think so!” (P18). One participant simply felt that exercise was not part of life before the stroke: “It wasn’t an important part of my life...I couldn’t be bothered” (P6) making it very unlikely that he would participate in exercise after the stroke.
Understanding of Stroke and Healthy lifestyles

Sub-categories that contributed to understanding of stroke and healthy lifestyles were: Role of exercise, Risk factors for stroke, Cause of Stroke and Lack of information or recall.

Understanding the role of exercise

When asked about their understanding of the recommended levels of exercise for their age only two participants offered explanations of the recommended dose: “I probably do three lots of cardio a week at least 40 minutes at a time” (P6) and “Everyone should do at least 10,000 strides a day” (P5). Other participants’ knowledge was clearly hazy and several incorrect interpretations of the recommendations were articulated, for example: “It’s not recommended to go every day” (P1) and “You’ve got to listen to your body” (P12). Most of the participants had not given the issue of exercise after a stroke much thought: for example, when asked ‘did you think about the appropriate amount of activity’ Participant 2 stated: “No definitely not”. Others made comments like: “I didn’t think about it, I didn’t realise that exercise could help with a stroke” (P3), “I didn’t really think about it if I am honest (P7)” and “I don’t really think about it much, I am just aware the more walking I can do the better” (P11).

Risk factors associated with stroke

Some participants were able to discuss some of the risk factors associated with stroke, for example, “it’s important to keep the weight down...have a sensible diet” (P1), “I don’t think it’s my diet because I am not a great eater of fried things and fatty stuff. And I am not obese” (P9), “oh yes like high blood pressure, high cholesterol, high blood sugars, smoking which I have stopped now” (P13), and “I’m not a smoker, I’m not diabetic, I don’t have high stress...” (P14). However, over half the participants were, rather worryingly, not aware of the risk factors that could lead to a stroke. As one participant who had diabetes said: “No I didn’t know there were any risks” (P15).

Cause of stroke

Over half the participants were unable to discuss what might have contributed to them having a stroke, for example, “Nobody has been able to tell me” (P2), “I don’t know how- do you get a blood clot” (P6), “No I don’t know, nobody has explained to me about that” (P15), “I don’t know really must have been some weakness in the brain” (P16), and “I haven’t a clue, I haven’t a clue” (P19).

A number of the participants did understand that knowing what might have caused the stroke would enable them to target the changes they made in their lifestyle and recognised the importance of such knowledge.
And because they don’t know why it happened that worries me a bit because it could happen again. (P13)

I don’t know what the root cause was which is somewhat unnerving because it could happen again unless I know what to do to prevent it...if they could determine the cause of the stroke for me because I can’t tell you whether I need to change anything because I don’t know (P14).

Lack of information or recall

When asked about any advice they had been given about exercise the main response was that they had been given specific strengthening and stretching exercises by the physiotherapist but very few talked about advice they had been given about maintaining their fitness:

“They don’t mention it [lifestyle issues] …nothing positive in terms of longer term options” (P2), “They didn’t talk about general fitness” (P6), “I haven’t been told anything” (P9), “Nobody has mentioned there is a benefit to exercise- that hasn’t been covered” (P14), “I was simply told I should only do so much and not overdo things” (P15) and “No - they said continue doing the things you’ve been doing” (P16).

One participant remembered being given advice about exercise post-stroke by the doctor:

The doctor let me do anything really he just said don’t lift weights …He didn’t really say one way or another, he didn’t say a lot to be honest (P13).

The participants’ responses, with respect to their understanding of the more general issues of healthy living and the importance of addressing these post-stroke, were cause for concern as they reflected a lack of information, for example: “Well they [health professionals] don’t go into great detail about it” (P5), “I haven’t been told anything” (P9), “Not a lot of information has been provided in all honesty” (P11), “Nobody’s said anything” (P12), and “Nobody has told us anything useful really, we’ve been using Google” (P20). As the last comment suggests some participants, particularly younger ones, did use and value, the Internet as a source of obtaining information. However, a majority of the participants, those aged over 60 years, felt they did not have adequate computer skills or were comfortable effectively accessing the Internet, for example: “I am not an online person” (P5), “No don’t know how to use a computer” (P7), “I’m not computer literate” (P9), “I don’t have a computer” (P16), and “No I only just about know how to use my phone” (P18).

Printed leaflets providing information about stroke and common risk factors were given by health professionals to some of the participants, but these did not seem to have significantly contributed to their understanding. As one participant (P17) said: “there was a lot of information leaflets at both hospitals. I just took them but I have not had a chance to read them. They were useful but perhaps if someone did actually say well look if you have this or do that”. It would appear that the participants were not given consistent or relevant information or advice about maintaining a healthy lifestyle or cardiovascular fitness. As
Hillsdon et al (2013) found in their study exploring patients’ experiences of standard care or cardiac rehabilitation post minor stroke and transient ischaemic attack, it is not always clear whether participants are able to recall the advice or information they are given. This raises issues of the nature, relevance and timing of health information and these require further research to ensure the effectiveness of these interventions for individual patients.

Discussion

The participants discussed a number of factors that prevented or made it difficult for them to engage in exercise but these did not include a lack of motivation. This is in contrast to previous studies (Nicholson et al, 2012 and Simpson and Eng, 2011) that focused on exploring the barriers and facilitators of exercise in the later stages of stroke recovery. It seems that it is important to work with people with stroke in the early stages of their recovery to encourage activity and to prevent perceived motivational barriers developing.

Participants in the present study identified a number of benefits of exercise that the Health Belief Model (Rosenstock, 1974) suggests could be beneficial to support their attempts to achieve a healthy lifestyle. The participants, however, did not discuss the benefits of fitness or prevention of future cardiovascular events, which suggests that they did not consider this to be part of the role of exercise after stroke. More research is needed to find the best way to support people with stroke in their efforts to understand and maintain a healthy lifestyle and explore the long-term benefits of healthy lifestyle after a stroke.

An area of concern, highlighted in the present study, was the doubts and lack of agreement expressed by some participants about the healthy lifestyle messages they had been given. This was also highlighted in previous studies (Forster et al, 2012 and Hillsdon et al, 2013) and emphasises the need for clear and consistent healthy lifestyle messages. Perhaps, more importantly, some participants appeared to welcome a chance to discuss their beliefs in order to address any doubts they had about the advice they were being given. This reinforces Forster et al’s (2012) recommendations that active information provision, such as, integrating the use of workbooks into experiential classes was much more effective than passive approaches, such as, the provision of information packs for use at home.

It appears that participants did not fully understand the factors that contribute to having a stroke. They were able to discuss some lifestyle risk factors but did not seem to make the link between these and having a stroke. This was also identified in a recent study by Hillsdon et al (2013) who found that ‘some disregarded information about known risk factors for minor stroke or that lifestyle changes can reduce such factors’ (Hillsdon et al, 2013:7). Effective health behaviour change relies on people taking ownership of their health behaviours, that is, switching from an ‘external locus of control’ (Rotter, 1966) to an ‘internal locus of control’. If, as illustrated in this study, people are unable to make the link between lifestyle risk factors and having a stroke then they are less likely to make lifestyle changes.

The American Stroke Association (2011) states that ‘patients with ischaemic stroke or TIA should be managed according to NCEP III guidelines, which include lifestyle modification,
dietary guidelines, and medication recommendations’ (American Stroke Association, 2011: 230). In order to modify their lifestyle, people with stroke need to be aware of exercise and dietary guidelines and recommendations, however, only two people with stroke in the present study were aware of the recommendations for cardiovascular fitness. This is not altogether surprising as a survey by the National Obesity Observatory (2016) found that only 6% of men and 9% of women in the general population had any idea about the recommended levels of exercise.

The present study also found that very few participants had been given healthy lifestyle advice. This mirrors the results of previous studies (Healthcare Commission Survey of patients, 2006, The Stroke Association, 2006, Furie et al, 2011, Forster et al, 2013) although, as with these studies, it is not clear whether this information was given but not fully absorbed and recalled by people with stroke. More research is needed to determine how to provide essential information, at what stage of stroke recovery it should be provided, and how to ensure that lifestyle changes are made and maintained as a result of receiving the information. People with stroke vary in their opinions about how relevant information could be provided. In the present study, only the younger participants expressed a preference for online information, the majority preferred to speak to someone to get advice. An associated study (Clague-Baker et al, 2015), conducted by the present research team, used focus groups in which the timing of lifestyle advice was discussed by a range of healthcare professionals working in stroke rehabilitation. It was found that most participants considered it was too early to provide lifestyle advice to people with stroke while they were still receiving care in an acute stroke unit and the team members, who provided care to people in the later stages of stroke recovery, felt that specific training would help them in effectively delivering accurate and relevant lifestyle information.

It has been theorised (Rosenstock and Strecher, 1998 and Bandura, 1977) that people wanting to make changes in their lives need to believe in the importance of those changes and feel confident that they can achieve the desired changes. In the present study, it appeared that over half the participants did not know any of the risk factors that could lead to a stroke and did not know why they had had a stroke. Without this knowledge it is doubtful that they would understand the importance of any lifestyle changes and have the confidence to make any change.

Finally, this study explored participants’ experiences and perceptions of healthy lifestyles before and after having a stroke. One limitation of the study was that participants who agreed to take part were keen to talk about healthy lifestyles and exercise and their interest in adapting their lifestyle after having had a stroke. As a result, these findings may not reflect a broad range of perspectives and experiences. Future research would benefit from actively engaging those people who are not as positive towards healthy lifestyles. A second limitation is that the average length of time after stroke varied from 14 days to 124 days and people’s perceptions may have varied over this time period.

Future Research
Future research needs to explore different types, durations and frequencies of exercise programmes that can provide cardiovascular training for people with sub-acute, mild to moderate stroke. Research is also needed to explore the best way to provide individual healthy lifestyle advice for the sub-acute stroke population in order to help them make individual changes and maintain changes throughout their life to help to prevent future cardiovascular events.

Clinical Messages

- Most people who have had a mild to moderate stroke in the sub-acute phase of recovery are eager to adapt their lifestyle and learn how they can best achieve these changes.
- At this earlier stage of recovery barriers to exercise such as lack of motivation do not appear to be an issue.
- Despite recommendations that emphasise the importance of educating patients about adapting lifestyle after a stroke, it appears that this is not occurring in practice and people with stroke have a lack of understanding of healthy guidelines, risk factors and cause of their stroke.
- They also do not appear to make the link between lifestyle choices and the cause of their stroke.

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Conflict of interest

The authors declare that there is no conflict of interest.

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