**Content**

The following supplementary files are included within this supplementary document. This has been developed to support the manuscript entiled Testing a Psychological tool to enhance hope in people with stroke; qualitative study:

**Content of supplementary document**

* **Supplementary file 1: The pilot study with results**
* **Supplementary file 2: The interview schedule**
* **Supplementary file 3: The development of the main analysis**
* **Supplementary file 4: The different versions of the MEAH**

**Supplementary file 1: The pilot study**

**A qualitative pilot study in factors contributing to hope level in stroke patient with MEAH Tool**

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Word count: 1500

**2a. Abstract**

**Objective**: To study factors that impact hope level of stroke survivors with the revised MEAH tool.

**Methods:** AnInterpretive hermeneutic phenomenological study was undertaken. Participants were included if they had suffered a stroke and attended a south Birmingham community centre. Individuals were required to participate in a single session at the community centre using the revised MEAH tool (appendix (a)). Data was collected from a semi-structured interview where observational strategy was embedded. Afterwards, data analysis using an inductive approach was used to capture themes.

**Intervention**: Individual interview by student physiotherapist to stroke survivors on July 5th and July 12th.

**Outcome Measure**: The outcome measures are difficulties that participants face in everyday life, the MEAH score, and their feedback from hope factors. The hope factors include personal goal, support from health-care professional and other caring network, and networking with other stroke group members.

**Key results**: Eight individuals with mean age 70.3 were included. Three results were identified. First, being able to walk again is important to rebuild hope. Second, the possession of goal and hope is related. Third, surrounding network could influence the goal setting.

**Conclusion**: The surrounding network of stroke survivors from health care professionals to families could affect the goal setting, hence potentially altering their level of hope.

**Keywords**: MEAH, factors of hope, stroke survivors, post-stroke difficulties

**2b. Implications for Rehabilitation:**

i) Goal setting design such as SMART goal could be effective for building up hope.

ii) Healthcare professional is important to keep a SMART goal in progress.

iii) Stroke survivors are encouraged to use self-referral services for community physiotherapy when they need to.

**3. Introduction**

**Problem formulation**: Stroke is an interruption of blood supply to the brain, resulting in brain damage and neurological deficit (Moskowitz et al., 2010). The cost of stroke to society is massive, costing £26 billion per year (Patel et al., 2020). The problem of stroke to an individual ranges from physical impairment, cognitive deficit to mental health problems (Ramos-Lima et al., 2018). Particularly important is their ability to look forward with hope and be able to identify goals (Visvanathan et al., 2019). Physiotherapists play an essential role in identifying goals and providing hope, although they can also be critical in the loss of hope (Soundy et al., 2010).

Effective communication is one of the keys to engaging patients to the therapeutic process, keeping them confident while continuing progress. On the other hand, poor interaction may not only confuse the patients, but also result in their hopelessness to the treatment. The model of emotions adaptation and hope (MEAH) is a tool that enables therapists to engage a discussion on hope in a short timeframe (Soundy et al., 2023). To enable a therapist to further the discussion with patients regarding hope to set the appropriate goal and strategy, a revised MEAH tool is suggested.

**Research aim**: This study aims at expanding the MEAH tool to include more questions on hope aspect. It is used to develop deeper understanding on hope and factors that influence hope in stroke survivors.

**4. Materials and Methods**

**4.1 Design**

An interpretive hermeneutic phenomenological study was undertaken. This type of study focuses on the meaning participants give to experiences (Alsaigh and Coyne, 2021). This research was situated within the paradigmatic world view of subtle realism (Duncan and Nicol, 2004). This looks at establishing common experiences or realities across different perspectives of people.

4.2 Reflexivity

The author was a 33-year-old male physiotherapy student in his year one of master’s degree.

4.3 Setting

The research took place in a single community location in south Birmingham.

4.4 Participants

The eligibility criteria of the research include people who had a stroke and attended a south Birmingham community centre. People who were unable to provide consent due to cognitive issue were excluded.

4.5 Sampling and Sample Size

A purposive sample of individuals was selected (Campbell et al., 2020). Sample size was determined on the principles of information power (Malterud, Siersma and Guassora, 2016). A sample sizes of 8 was aimed for in-depth exploration to achieve saturation (Hennink and Kaiser, 2022).

4.6 Ethical issues

The study is approved by the Science, Technology, Engineering and Mathematics Ethical Review Committee (Reference: ERN\_22-0410).

4.7 Procedure

The intervention was conducted in common room of the community centre, where it serves as a hub for stroke survivors to participate activities and support program. It was conducted individually while the rest of stroke group were having other social activities.

The intervention description is given below (Beavers et al., 2020):

Who: A student physiotherapist who had no previous engagement with the group.

What: An individual interview with respondent. Answer would be recorded on laptop.

Why: The intervention utilized the MEAH tool to capture the psychological adaptation of stroke survivors to further understand what contributes to their hope to face the difficulties.

When: On July 5th and July 12th between 10am and 12pm (see appendix (b)).

4.8 Data collection methods:

The study combined a semi-structured interview and observational strategy to collect data on difficulty of daily living, and the perception of various hope factors. The interview would follow an iterative process to further understand their stroke experiences. Based on interview data, observation and contextual factors, the triangulation method would be employed (Carter et al., 2014).

4.9 Data processing:

Interviews responses were transcribed and reviewed for accuracy. Each interviewee was given a unique identifier and data would be analysed in a systematic way.

4.10 Data analysis:

An inductive approach was used to capture the themes from their stroke story. Repeated reading to data would be done to gain a holistic picture of the participants’ experiences (Byrne, 2021). Connections and patterns would be recognized (Thomas, 2006). The whole process would be done by the student physiotherapist. An audit trail of the processes can be seen in appendix (appendix (c)).

4.11 Techniques to enhance trustworthiness:

Triangulation from observations, interview notes and relevant literature would be included to formulate the data source to develop a complete understanding (Braun and Clarke, 2020).

**5. Results**

Demographics

Eight stroke survivors had participated the interview on July 5th and July 12th, 2023. With 5 males and 3 females, half participants had stroke history of over 10 years. Six of them had been members of the stroke group for over 1 year. The demographics can be seen in Table 1.

Table 1. Demographics of participants.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Number | Sex | Age range | Years with stroke | Live alone /  with family | How many months / years of participating stroke group activities |
| 1 | M | 80-90 | Not remember | Family | 1month |
| 2 | M | 70-80 | 15-20 | Family | 1 year |
| 3 | M | 60-70 | 10-15 | Family | Many years |
| 4 | F | 70-80 | 5-10 | Alone | 3 years |
| 5 | M | 70-80 | 0-5 | Alone | 1 year |
| 6 | M | 50-60 | 0-5 | Alone | 1month |
| 7 | F | 50-60 | 10-15 | Family | 9 years |
| 8 | F | 70-80 | 15-20 | Family | Many years |

Synthesis

The results are presented in two major areas of focus. First, the relationship between the identified difficulty and the scores are examined. Following this the suggested factors of hope and its impact are explained. Finally, themes are identified based on inductive thematic analysis.

Synthesis finding 1: relationship between difficulty and scoring of the MEAH.

Three main difficulties were identified in response to the initial open question from the MEAH. Table 2 synthesizes these difficulties.

The first difficulty identified by one participant was the inability to walk. He was ceased from playing his favourite ball game given his wheelchair-bound condition, resulting in low hope and energy.

The second difficulty identified by 5/8 participants was walking with difficulty. This condition had slowed down their daily lives rhythm from grocery shopping to walking the park. However, they still maintained either middle or high hope given their independent ability to engage outdoor activities. As a result, 4/5 felt pleasant and 3/5 felt energetic in their life.

The third difficulty identified by 2/8 participants was weakness and speech problem. One of these 2 participants could barely speak, so his MEAH score was indicated by hand gesture. Another participant remained unaccepted to his condition. He was unsure if he should have hope, so he had no comment. His energy and feeling remained at middle level.

Table 2. Relations between difficulties and MEAH score.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Difficulties | No. of  participant | Level of hope | Level of acceptance | Level of energy | Level of feeling |
| **Inability to walk** i.e. Wheelchair-bound | 1 | Low | High | Low | Low |
| **Walking with difficulty** i.e. walk slowly or walk with stick | 5 | Middle (n=2) High (n=3) | High (n=5) | Middle (n=2) High (n=3) | Middle (n=1) High (n=4) |
| **Body weakness and speech problem** | 2 | Low (n=1)  No comment (n=1) | Low (n=2) | Low (n=1)  Middle (n=1) | Middle (n=2) |

Synthesis finding 2: personal and environmental factors that could influence hope.

In terms of personal goals, 3/8 had no specific goal, 2/8 had goal to walk again or walk longer. Two had outdoor activities goal such as travelling. One had a goal to enjoy life. For HCP support, only 1/8 was currently receiving physiotherapy. For caring network, 5/8 had received relevant support. As to taking part in stroke group activities, all expressed happiness and positivity of their participation. A summary can be seen in Table 3.

Table 3. Different factors and findings.

|  |  |
| --- | --- |
| Factors | Findings |
| **Personal goal** | * Two had walking-related goal. * Two had goal to go outdoor more. * Three had no specific goal. * One had a goal to enjoy everyday life more. |
| **Health-care professional support** | * One was currently receiving physiotherapy, three had tried physiotherapy before. * Four had never received physiotherapy. |
| **Other caring network support** | * Five identified receiving carers or family support. * Three had neither support from carers nor families. |
| **Networking with stroke group members at community centre** | * All of them expressed happiness when making acquaintance with other stroke group members in community centre. |

Synthesis finding 3: Thematic analysis.

Three themes are summarized. First, being able to walk again gives higher chance to rebuild hope. By regaining independence, a survivor has higher chance to live life approximate to before stroke. Second, setting an appropriate goal with progress checkpoint could keep a survivor seeing what lies ahead and remaining hopeful. Third, the survivors’ closed network could provide caring and professional support, keeping them more motivated to reach their goal. A summary can be seen in Table 4.

Table 4. Different themes and findings.

|  |  |
| --- | --- |
| Theme | Findings |
| 1 Being able to mobilize is important to rebuild hope | * Rebuilding sense of independence and self-esteem. * Less restriction from activities participation. * Higher chance to live life approximate to before stroke. |
| 2 The possession of goal and hope is related. | * Types of goal e.g. realistic vs unrealistic. * Goal setting can be further categorized into short term, medium term, and long term. |
| 3 The importance of people factors to goal | * Professional network such as physiotherapist could help patients understand the condition they are facing. * Caring network could provide support and assist daily activities, giving more motivation to them. |

**6. Discussion**

**Relations between goal setting and hope.**

Hope is a critical coping resource for stroke survivors as it signals a life that is worth living (Taule et al., 2015). It does not only improve emotional distress, but also treatment result and quality of life (Bright et al., 2011).

Specifically, having an outcome-related hope such as a goal gives a person direction in life, so they become more engaged in rehabilitation (Bright et al., 2020). This is different from a broad sense of hope, in which a goal keeps a person realistic in the process with an assumption this will help their recovery (Soundy et al., 2010).

**Relations between supporting network and goal setting.**

Though unsure if caring network would affect goal setting, larger baseline network is associated with better physical recovery. This could be due to a more cohesive network post stroke, where the caregiving condition is better coordinated (Dhand et al., 2019).

Also, in physiotherapy goal setting is one of the patient-centeredness approach when working with patient (Melin et al., 2019). Therefore, a collaborative goal setting is made more likely and feasible (Lloyd et al., 2013).

**Implications for rehabilitation**

Given the importance of goal setting, physiotherapist could set SMART goal for stroke patients. This ensure the goal to be both achievable and relevant. With the goal continuing to be reviewed and progressed, a patient would gradually live a more functional life.

Also, a patient is encouraged to self-refer for community physiotherapy if they struggled to improve in their functional life.

**Limitations**Given the vast spectrum of stroke survivors, a sample size of eight could be insufficient to reach data saturation. Also, the interview setting is in the common area where distraction may affect the interview quality.

**7. Conclusion**

The surrounding network of stroke survivors could affect goal setting, hence potentially altering their level of hope.

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**9. Appendix for pilot study**

Appendix (a): Revised MEAH tool

|  |  |  |
| --- | --- | --- |
| **Patient info** | Name |  |
|  | Gender / Age |  |
|  | Social history |  |
|  | 1st stroke info / 2nd stroke info |  |
|  | How long (mth/yr) have you participated in the community centre activity? |  |
|  | Email |  |

|  |  |  |
| --- | --- | --- |
| **Area** | **Question** | **Answer** |
| Q1:  Difficulty **In general** | Which aspect / area of life you are finding difficulty to adapt to after stroke? |  |
| Q1 – extension:  Difficulty  **Role and identity** | Are there any change to your role and identity that you may not fulfil after stroke? |  |
| Q1 – extension:  Difficulty  **Participation of activity** | Are there any restriction to your participation of activity on individual level or social level? |  |
| Q1 – extension:  Difficulty  **Everyday functions** | How did stroke change your everyday life functions? |  |
| Q2:  MEAH  **Hope** | Hope - How hopeful are you right now you can change this difficult condition? | High (i.e.hopeful) / Middle (i.e. accept it could not change) / Low (i.e. no hope) |
| Q3:  MEAH  **Acceptance** | Acceptance - To what extent are you currently able to accept this difficult condition? | High (i.e. embrace) / Middle (i.e. acknowledge) / Low (i.e. not accept) |
| Q4:  MEAH  **Energy** | Energy - How much energy do you have to deal with this currently? | High / Middle / Low |
| Q5:  MEAH  **Feelings** | Feeling - How do you feel about it ranging from positive/pleasant to negative/unpleasant? | High (i.e. pleasant) / Middle / Low (i.e. unpleasant) |
| Q6:  Change of hope over the course | Over the course of your recovery journey, do you experience any change in hope? |  |
| Q7a:  Factors that could impact hope  **Personal goal** | Do you have any personal goal now?  If yes, do you think the goal has / will give any impact on your hope?  Do you think you can use this difficulty as your goal?  Have you ever thought about living your life again with less restriction from this difficulty? Why? |  |
| Q7b:  Factors that could impact hope  **Physiotherapy support** | Do you receive physiotherapy now?  If yes, does physiotherapy give you any impact on hope?  If no, do you think exercise can help your condition? |  |
| Q7c:  Factors that could impact hope  **Caring network** | Who is your closest caring network? Are they paid or non-paid carer?  Do they give you any impact on hope?  i) In terms of presence, ii) wording of encouragement / discouragement, iii) suggestion on how to change the difficulty? |  |
| Q7d:  Factors that could impact hope  **Other people with stroke experience** | In the past, do you know anyway close with you who has stroke?  In community center here, what do you observe and what do you get from being here?  Do these community stroke members give you any impact on hope / stress / comfort?  Do you want to continue to join and enjoy the social environment? |  |
| Q7e:  Other factors that could impact hope | Do you have any other factors that could give you an impact on hope?  i) faith in yourself, ii) spiritual belief, iii) others? |  |

Appendix (b): Interview schedule

|  |  |  |
| --- | --- | --- |
| Schedule | July 5th | July 12th |
| 10:20am | 1st interview | 1st interview |
| 10:40am | 2nd interview | 2nd interview |
| 11:00am | 3rd interview | 3rd interview |
| 11:20am | 4th interview | 4th interview |

Appendix (c): Audit trail

A diagram of a process

Description automatically generated

**Supplementary file 2**

**Version: 1.4  
Date: 21/1/2022**  
Semi-structured interview for process evaluation: people with stroke

**Section 1: General questions**

Can you tell me about your experience of taking part in this intervention?  
Was there anything that stood out about it? Can you explain what that was?  
Do you think it could be applied to practice and in placement?

**Section 2: Perception and experiences of the screening and intervention**

Considering the questions asked were you happy with the number of questions and the  
areas that were considered?  
What was good or not so good about this screening and intervention approach? Can you  
explain why?  
Were there any benefits associated with taking the intervention? Can you explain what  
these were OR can you identify why there weren’t any?  
Can you consider if these questions would be valuable to people who are in hospital with a  
similar condition as yours? Can you explain why or why not?  
Was the length of time and level of content appropriate? Can you explain your answer?  
Would you like the process to change? If so how?

**Section 3: Future application of the intervention**  
Do you think this has a role in supporting people with neurological chronic illness?  
Do you think the intervention should be used for physiotherapists more widely? Can you  
explain why?

**Supplementary file 2**

**Version: 1.4  
Date: 21/1/2022**  
Semi-structured interview for process evaluation: Physiotherapy students taking part in the intervention: Interview for students

**Section 1: General questions**

Can you tell me about your experience of taking part in the placement?  
Was there anything that stood out about it? Can you explain what that was?

**Section 2: Perception and experiences of the training, simulation practice and  
placement**

What was good or not so good about the training you received?  
Were there any aspects of this training you would change? Can you explain why?  
Are there any benefits associated with taking the training? Can you explain what these  
were OR can you identify why there weren’t any?  
What was good or not so good about the MEAH extended interviews? Can you explain  
your answers?  
Are there any benefits associated with the MEAH extended interview? Can you explain  
what these were OR can you identify why there weren’t any?  
From the above questions about the intervention, if there were to be changes to the  
intervention what should these be?

**Section 3: Future application of the placement**

Do you think the intervention should be used for student physiotherapists more widely?  
Can you explain why? and when you believe it would be useful?  
Do you think the intervention could be integrated into a university course? Can you  
explain your answer?  
Can you see or suggest any other avenues for application? E.g., post qualification?

***Supplementary File 3: The analysis***

*Full analysis tables*

*Table 1 A table identifying individuals’ responses to hope, acceptance and energy split by those who could and were not able to create goals.*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Item | **High** | **Average (middle)** | **Low** | **No answer or answer unrelated to scale** |
| Hope for change to be accomplished | Goals: 4,9,11,15,16  N=5/11, 45%  No Goals:  N=0  Total number of participants:  4,9,11,15,16  N=5/17,29%  ***Examples quotes***  *Always hopeful. But after, after a while, you realize that you're the same person, you just a different version* (P15)  *I’m… what’s the word… optimistic. I expect to get things right, I'm like that.* (P16) | Goals: 7,8,12,13  N=4/11, 37%  No Goals: 1  N=1/6, 17%  Total number of participants:  1,6, 7,8,10, 12,13,14  N=8/17, 47%  ***Example quotes***  *I think it is possible it might change. There is some hope that it could be improved but I am not sure. I think it is the middle one* (P1)  *I’m not really hopeful about it changing, but I’m hopeful that I can manage it* (P12) | Goals:  N= 0  No Goals: 2,3,5,14,17  N=5/6, 83%  Total number of participants:  2,3,5,14,17  N=5  ***Example quotes***  *None, they’ve told me that there is nothing they can do and it is permanent….They can’t repair it.(P2)*  *I don’t think I’m ever gonna change, I have no hope*. (P3)  *I see no hope and no change. Cause I have got 3 strokes and bowel cancer* (P5) | Goals:  N=0  No goals: 0  N=0  Total number of participants:  N=0  ***Example quote***: |
| Acceptance of difficulty currently | Goals:  N=0  No Goals: 1,3  N=2/6, 33%  Total number of participants:  1,3 n=2/17, 11%  ***Example quotes***  *I think I’ve embraced it. I know that it’s something that has changed since the stroke and that it’s something I need to work on in order to make it better (P1)*  *Yes I have accepted it completely. It’s a part of me now. (P3)* | Goals: 6,7,8,10,12,13,15,16  N=8/11, 73%  No Goals: 2,17  N=2/6, 33%  Total number of participants:  2,6,7,8,10,12,13,15,16,17  N=10/17,59%  ***Example quotes***  *I accept it and I am learning to live with it because there is nothing else I can do really* (P2)  *I accept that my husband will never come back, it was COVID, I couldn’t see my husband*  *at all when he passed away. That was a lot to accept, but I accept it a bit more now* (P6)  *I acknowledge it. I think I have a middle ground response* (P12) | Goals:4,9,11  N=3/11, 27%  No Goals: 5  N=1/6, 17%  Total number of participants:  4, 5,9, 11  N = 4/17, 24%  ***Example quotes***  *I’m not going to accept it, no* (P4)  *I acknowledge it…I don’t think I shall ever accept* it (P5)  I don’t accept it, I won’t accept it (P9)  *well it’s hard to accept* (P11) | Goals:  N=0  No Goals:  N=0  Total number of participants:  ***Example quotes*** |
| Energy towards difficult  How much energy do you have to deal with the difficulty | Goals: 6,9,10,16  N=4/11, 36%  No Goals:  N=0  Total number of participants:  6,9,10,16  N=4/17,  ***Example quotes***  *Well I suppose high energy really* (P6)  *Yeah, plenty of energy, yeah* (P9)  *I practised every day and now I can do it all… Oh it's hard work, I’m tired* (P16) | Goals:4,7,9,11,12  N=5/11, 45%  No Goals: 1,2,3,17  N=4/6,  Total number of participants:  1,2, 3, 4,7,9,11,12,17  N = 9/17  ***Example quotes***  *I find that I don’t actively use up my energy to try and practice. I think only average energy* (P1)  *On the scale I would say average energy because there are times where I don’t think about it at all, but when I’m outside I really do* (P3)  *I use a FES on my leg and that saves about 10% of my energy. I was using far more energy without that. As long as I’ve got my FES device for my leg, I’ve got use to it, I don’t really use that much energy* (P12) | Goals:  N=0  No Goals: 5  N=1/6, 17%  Total number of participants:  5,13  N= 2/17  ***Example quotes***  “*I don’t think I have got any energy, no energy both mentally and physically* (P5) | Goals:13,15  N=2/11, 18%  No Goals: 14  N=1/6,17%  Total number of participants:  P13,P14,P15  N= 2/17  ***Example quotes***  Interviewer: *So how much energy do you have to deal with this currently?* P15: -  *I find I get tired faster but i never did anything before or if i push myself too far* *Sometimes I don't have any energy… Big challenge, and partly having those people around you. To motivate you… got to think positively, got to push yourself, push your limits to really* (P13) |
| Feelings  How do you feel about the difficulty currently from positive or pleasant o negative or unpleasant | Goals:1,10,16  N=3/11, 27%  No Goals: 1,14  N=2/6, 33%  Total number of participants:  1, 4, 10,14,16  N= 5/17, 29%  ***Example quotes***  *Do it because it makes me feel better because I can still do it (driving*). (P10)  *You have to be positive. If you're negative, you might as well kill yourself*. (P14) | Goals: 6,7,8,9,11,P13,P15  N=7/11, 64%  No Goals: 1,17  N=2/6, 33%  Total number of participants:  1,6,7,8,9,11,P13,P15,17  N = 9/17, 53%  ***Example quotes***  “*I have average feelings. It’s not something that stresses me out day to day because I don’t have to think*  *about it every day. Compared to what I have achieved, it’s not a massive challenge*” (P1)  *Normal feelings, in the middle* (P6)  *more in the middle really. Depression is a thing and an important part of the stroke because you lose all your ability and get confused and in your head* (P11) | Goals:12  N=1/11, 9%  No Goals: 5  N=1/6,17%  Total number of participants:  5,12  N=2/17, 12%  ***Example quotes***  *I hate it I can’t walk* (P5)  *It’s an unpleasant experience*. (P12) | Goals:  N=0  No Goals: 2,3  N=2/6, 33%  Total number of participants:  2,3  N = 2/17, 12%  ***Example quotes***  *I have no feelings towards it at all really. It’s just something that I’ve had to learn to live with now so I*  *can’t change that. I accept it and that’s it. I don’t sit and feel sorry for myself or anything like that. I know it’s*  *not gonna get better so I’ve learnt to live with* it (P2)  “*I don’t think anything towards it at all because I’ve accepted it. I’m not gonna get back to the way I was.*  *This is how I am now so I have no feelings towards it. No one has ever asked me questions like this so I*  *haven’t really thought about it.* (P3) |

Note: Goals: Participant who wanted to set goals, No Goals: Participants who did not have or want to set goals:

***Group that set goals***

Being more patient, because it’s going to take time. (P4)

Well they have said about going to the coffee mornings by where I live, so maybe I could do that. (P6)

Very keen to walk independently again (P7)

Wants to go on a seaside holiday trip but is worried about travel and stress on wife. Wants to achieve this soon as feels later in life won’t have the ability. (P8)

Pick up golf again. (P9)

P10 didn’t answer the question but identified that he had set a goal of driving and achieved that and to continue driving was an important part of the interview. (P10)

I need a rail fitted on my stairs so I can up and down the stairs (P11)

I set all my own goals myself. The only one I didn’t achieve was riding a bicycle, but apart from that I achieved them all. My main goal at the moment is to further my research and do a major presentation at [prestigious stroke conferences].” (P12)

I want to be able to… the target is to be able to jog. Probably not long but more and improve coordination [Inaudible] so I can really move around. (P13)

I’ve got goals : the gym, swimming, driving, running but I’ve got to go, once i get into the routine of something thats the easy part, but it’s starting it. (P15)

I let it roll. When I get better, I’m chuffed. [explains how they are getting better with people’s names…now]. Before I couldn’t do that. With the alphabet, I couldn’t remember it, I couldn’t say it. Little goals. In the hospital I would try to remember words and think about it and remember names. (P16)

***Group that did not set goals***

No, I’m happy as I am. If I want to write better then I can practise but I don’t think I need any goals because it’s not affecting me that bad. (P1)

No, I don’t think about the future, I just think about today. I am happy as I am and don’t want to think about setting goals for the future. I know there is nothing I can do, I can’t alter anything, so might as well learn to live with it and look forward to the next day (P2)

I don’t really have goals. I just am where I am now and that’s it. The only thing from the stroke is no alcohol or caffeine which is annoying, but that’s not because of my balance so it’s fine. But because my brain is slow from the stroke, I don’t really think much about goals or anything. I just take everything day by day. I might think about it more tonight and have a real think but, no. I’m as normal as I can be. (P3)

Interviewer: Are there any goals that you could consider that could help with the difficulty? P5: “No, nope I have nothing (P5)

Interviewer: So is there a goal we could, we could consider that would help difficulty? P14: No (P14)

Interviewer: “How about any tasks or accomplishments, are there any changes in those?” P17: “I’m 54, I’m happy with what I’ve got. I’ve got no goals in sight. I: “Are there any goals you have set?” P17: “Just to get on my next holiday [laughs] (P17)

Exploring the difficulty further

|  |  |  |
| --- | --- | --- |
| **Area** | **Question** |  |
| Difficulty extension  **Change** | Does the way you think about the difficulty change over time? | Goals group  Worse over time (P4;P6; P10) – since pandemic (P10)  - same or unchanged(P8;P9) - Having to cope with effects over time (P8), have to work hard to improve situation (P9) or manage your situation (P11) had to empower myself , have a routine, write things down to cope (P13), your brain takes longer but you can do it (P15)  Managed to understand it and control it (P12) situation has improved consistently and is getting better (P16)  No Goals group  No change – when writing it take energy and gets worse as more is done (P1), know what to expect (P2), got used to the changes (P3), have made some lifestyle changes (P17)  Goals: 4,6,7,8,9,10,11,12,13,15,16  It has got worse and harder to deal with overtime” (P4)  Well yes, it (Parkinson’s disease) has made it worse really, because I also fell and was in hospital for a week. I had a scan on my head to see if I had done any damage, so I am a little bit scared now and think that I need to be careful (P6)  I do think differently yeah, I miss my husband and over the time it has got worse because I miss the help and having someone to talk too. My situation has changed (P6)  Was the provider for the family but now dependent on the family and doesn’t like that. Had to retire from after stroke but was working prior. (P7)  Coping day in day out and has been that way since the stroke. (P8)  Never has or will accept the stroke but has worked hard to improve out of necessity. (P9)  It has gotten worse since the pandemic. And that’s because I wasn’t doing anything close to what I was doing previously (P10)  Yeah, I think about it more, my brain looks for solutions to the problem, so that’s a good way of thinking now. It was an important thing when I was in Moseley Hall, they were telling me you would get dressed and whatever, well they’re basically didn’t do a lot. You find the nursing staff, they’ll look after you and encourage you to be yourself, there’s a lot of that. It is a shame. But I give myself my own pills now, that kind of thing. But you find a lot of people do a bit too much stuff for you and not let you think about what you’re doing (P11)  Yes, because as I’ve begun to understand it, I now can control it. Understanding something gives you  hope. When you don’t understand something you have despair. I don’t advocate what the medics say about not being able to give people hope because you might give false hope - because nobody talks about false despair, and that’s the evil twin of false hope (P12)  Well. It’s changed that I have to kind of empower myself. I have been in a car accident, I’ve been damaged. [Inaudible] you know, I can do it (P13)  Initially was, you know, you still forget things, but I just have to, you have to have a routine, very strict routine. And write things down. And I don't get me down as well as meeting people forgetting their names. But, no, I've got people. (P13)  Probably, because when it first happened you thinking that it's the end of the world and now it's just a same me just a different version. It’s all still there just it takes longer to find the end. Before you look at that and you just fix it, but now they say your brain is like a SATNAV, and because this happened you have to go another route. You’ll still get there just your brain is working harder and struggles to get there as fast. (P15)  oh it's better now since when I had it. All the time I think positive I just keep thinking better, better, better.” (P16)    No goals: 1,2,3,5,14  P1: I think it has changed a bit over time. I could write normally before my stroke. Even since my stroke it’s changed though. I start off alright, but then the more I go it gets smaller and smaller and I can recognise this as it happens. It’s been like this the whole time since my stroke though. I have to really think about it to try and get my writing normal and I get frustrated because it’s taking more of my energy. The longer I try to write the harder it is. If it’s something short it’s fine, but when I write longer things I notice my frustration. (P1)  Oh no nothing has changed. Since I know that it’s permanent, the way I feel hasn't got any better or worse really. It's been a while since my stroke so I know what to expect and what has happened. (P2)  “No, I think I’ve covered it. Over time I have got used to changes that have happened in my life. I don’t think there will be any change in how I think now because it’s been a while (P3)  “no. as regards to stroke I’m not worried about it in the slightest, a few lifestyle changes. No smoking, drinking or partying until 4 in the morning. So I know I'm doing everything I can to prevent another. (P17) |
| Difficulty extension  **Role and identity** | Does the difficulty impact on any important roles (parent/someone who works) and/or identities/groups (sports group, community group) that you associate(d) with? | Goals  Unseen nature family don’t appreciate it (P4) others don’t appreciate the struggle and suffering (P13)  Dependent on family (P4), family have to act as carers which adds stress (P7), wife as carer and worried about stress on her (P8), supportive son (P10), more dependent on wife around the house (P12)  Loss of contact only see daughter (P6) continuing to live independently regardless family worried about an accident occurring (P9), reduction in contact (since COVID) (P10), cannot drive anymore (P11) friends don’t come to see you (P15)  No goals  No impact (P1; P2; P3; P17) doing what could be done before (P2) apart from stroke group doesn’t go out (P3)  Prevents bowls (P5)  just frustrating (P1)  More cautious about gardening and what is taken on (P2)  Daughter supports (P2)  Goals: 4,6,7,8,9,10,11,12,13,15,16,17  “It does because family don’t understand, they just see the physical effects and think that’s it. They don’t realise that there is much more.” (P4)  “I’ve become more dependent on family (P4)  “That’s a difficult situation, I only come here, I don’t really see anyone, only my daughter  once a week” (P6)  *Has carers come to the house, but family have to act as carers as well which adds extra stress. (P7)*  *Wife full-time carer who is coping but feels down now and again. Very concerned for the stress on her. Wife has to do jobs as the stroke has limited use of right hand. (P8)*  Family scared of an accident or fall, quite protective but will continue living independently regardless. Wife passed away 10 years ago so lives alone with no support. Aware can get unnecessarily aggressive (P9)  *I’ve got a supportive family. My son only live about 10 miles away. [inaudible]. I used to go over every 2-3 Sundays over the years to and vice versa. Pandemic I didn't see him for three years. He started going back over we have we've been over once this year. Because it a 110 mile way. (P10)*  *Because my arm doesn’t naturally go down. Especially in the cold….I gave in and bought an automatic. And to be fair I wish I had done it years ago. It so easy. Just put your foot down and go. (P10)*  I mean I can’t drive anymore.” (P11)  It means I can do less around the house to help my wife. Since COVID-19 I’ve started cooking more and I enjoy that. But if my muscles in my hemiplegic side aren’t working very well then it’s a bit more dangerous. If my fatigue is bad then I might make mistakes cognitively. I don’t drive when I have extreme fatigue. Most of my groups and interviews are done online soI can do them. I know if I have a bad day then I know to say that, but it doesn’t really affect me (P12)  *Yeah, some people probably think I am being a bit rude. Like they think I can sit there a bit longer and they think that I am just ignoring them. [Inaudible] I’d like to think some other friends would be more understanding, but they just don’t understand it, accept it.* They’ve got to understand what I'm really going through [Inaudible] “She’s put a face on, surely it can’t be that bad”. But they don't know what I'm going through that’s why I'm really suffering and struggling and knowing that respect. [Inaudible] I don't always wanna think about pain because there are other things in life I can talk about. The only people that really know about my pain are my family.  *(P13)*  *the main thing with this if you find out who your real friends are. Before that they all come to see you but once this happens you see them much less. It sorts the weak out from the rest. Like you’ve only ever get a handful of friends, true friends, anyway. There were 8 of us at [name of NHS rehab facility], there are 3 of us now and we make sure to meet up once a fortnight and thats going to be there for life. And thats going to be a massive bonus out of that. With family, you appreciate more where you use to take for granted in the past, but they're always very good. You tell them you love them more, hug them more. You just realize that the people that are close to are the people that are most important. If you meet anybody else on the way, that's a bonus, but, that group there, that’s the magic point. With the [name of NHS rehab facility] group, because we’ve all gone through the same thing, you cant dislike people for not getting involved, but because we’ve been through the same thing we don’t have to go through the background of how you ended up here, you can just enjoy the now. (P15)*  “yeah, it slows you down, it's like that problem. But if I can work better then I can communicate when I get the words so people understand what I am saying. (P16)  Well, I can work a phone to push the buttons because my arm is affected by the stroke, and using a fork and spoon. (P16)  )  No goals: 1,2,3,5,14  P1: No (it doesn’t impact on groups or roles) it’s just frustrating to me whenever I do need to write. But as I said before, it’s not something that I really need in my day to day life.  “I can do most things I used to be able to do within reason. Obviously I can’t bend down as much as I used to and things like gardening, I can’t put my head down for long periods of time. It’s a little bit restricting, but not alot.” Interviewer: “Can you tell me more about your gardening post stroke?”. P2 - “ I still do my gardening, but I have to watch a lot. My daughter does a lot of it and I see what I can do, but because of the leaning down I can’t do as much as I used to. I have to be cautious because I don’t want to fall over and that's what happens when I lean forwards a lot. But it makes me happy (P2) Interviewer: Are there any other activities that you maybe were doing post stroke that you still can or cannot do?”  P2 - “Not really. I think I’m doing everything I would have been doing before. It hasn’t altered my life that much really. I’ve still got all my arms and legs and I’m doing well so I feel happy about what I can do.”  “No not really. Apart from coming here [stroke centre], I don’t really go out. I live in a flat on the 5th floor so I can’t do any gardening, but that’s not because of my balance or anything. I’m not limited but my balance. At home I’m fine, I do my cooking and everything else. I used to have carers come, but they did a questionnaire and they said I didn’t need them anymore so they cancelled them. P3  “It affects my sports because I used to play crown green bowls and I can’t play that anymore (P5)  “Well I guess so, I cannot do the things I want to do and used to enjoy, it has changed me” (P5)  To this one (coming to the stroke group)\_, there is no problem, because my son brings me (P5)  no not really (P17 |
| Difficulty extension  **Social Participation of activity** | Does the difficulty influence, change or impact meaningful relationships you with others who are close to you? | Goals  No change in relationship to family (P6; P12; P15)  Sees family, children, grandchildren more (P8)  Looked to make more friendships as struggle with loneliness (P9) have arranged to get friends to take them out (P11)  Don’t see family as much (P11)  No Goals  No change (P1,P2, P5, P14, P17)  Goals: 4,6,7,8,9,10,11,12,13,15,16,17  Interviewer: “Did you find that you did the crafts before you had a stroke?”  4: “No, it’s something new, I was too busy at work before to think about those things.” (P4)  Umm… I don’t know, I don’t think so. She rings me every night on the telephone, and  this has changed, we never used to speak that often (P6)  Has had a large impact on family with 3x children, 7x grandchildren and 2x greatgrandchildren. Sees them more now and feels closer to everybody but does not feel the same in themselves. (P8)  Struggled with loneliness and always liked meeting people since professional life. Since the stroke has actively looked for ways to make new relationships like dance clubs pre covid 19 pandemic. (P9)  I’m not at the moment, no. We are arranging for a few ladies to take me out one day. It would be nice to get in a group or whatever (P11)  Well I’ve got my son and my sister, I’ve got two brothers and two sisters that live on the other side of Birmingham. When you’re ill people don’t know you, they forget and that. They don’t come to see me anymore, but that’s families (P11)  well I’m a religious person, but I do feel a bit let down by the church because the priest still hasn’t come to see me, it’s hard when people don’t follow through with their promises. Especially with carers I like to know that if they say they are coming they will come because they really help me a lot” (P11)  “Not anymore. It did in the first few years after my stroke. I have three sons and they were teenages. It impacted them because my personality changed. I became withdrawn, my sense of humour changed, and that was hard for them. Now it’s good, I have seven grandchildren and that’s given me a new focus. There are things I can do with them, but I can’t pick them up, which is really frustrating. But I’ve gotten used to it by now (P12)  I find that because people like family, knew who I was before, and the change they've accepted it. It’s the same person just a different version. But people from outside, I’m in a relationship at the moment you I didn’t know before. She gets frustrated because she's very direct and if you can see the solution you do that. (P15)  oh its difficult, with my wife its difficult because she is like deaf its difficult, but otherwise no problem” (P16)  No goals: 1,2,3,5,14,17  P1: No, because it’s just my writing (P1)  “Not really. My family are more careful with me now and they realise that I can’t do this or that anymore. They are more aware. They are good, they take care of me. (P2)  No, it hasn’t (P5)  No. I mean, I've, I've got good friends. And they know im a little stupid, they know what happened, but no not really. (P14)  No (P17)  “I’m 54, I’m happy with what I’ve got. I’ve got no goals in sight (P17) |
| Difficulty extension:  Difficulty  **Everyday functions** | Does the difficulty influence, change or impact tasks or accomplishments you would like to make? | Goals  Yes (P6;P7; P15; P9; P10:P11; P16)  basic tasks and support would be valued (P6)  would like to walk again (P7) would like to do the half marathon and full marathon but it will take longer (P15)  limits gardening and cannot do to much, only can do the washing up cannot do ballroom dancing (P9) limits eating, reading and being able to concentrate (P11) working a phone is possible and using a fork and spoon is possible (P16)  No (P12) being able to do more because of opportunities  No goals  No (P1;P2;P5; P17)  Happy with what can be done (P1;P2) or they have (P17) and accepted it (P5)  Goals: 4,6,7,8,9,10,11,12,13,15,16,17  Yes, basic tasks and having someone there to talk to and support me, I miss the company” (P6)  *Very keen to walk independently again. (P7)*  *I used to do the black country to Birmingham half marathon and I’ll do a London marathon. Well now you’ll need a good time keeper to wait for me to finish. I’m still going to improve my fitness, because I’m not useless but I’ve lost a lot of strength and then you get into that stage where you say you’ll do it (P15)*  Tried gardening, used lawn mower but can’t do too much. Other household chores tried to help with but can’t, only doing the washing up. (P8)  Lives completely independently, ballroom dancing is only activity can’t do. (P9)  I started going to physio 2008. I started going to the gym in 2010. But I’m still having the physio at the hospital. People don’t believe me when I said I’ve been going to physio for 2 years. (P10)  “I’ve got a kindle, and sometimes when I try to read the kindle like I used to, it’s a good activity but I’ll get the kindle and I can read it and log into it. But I struggle to concentrate on the chapter and I’ll probably read the same line about ten times. (P11)  Yeah, eating. It’s a basic task and I’ve got a special knife and fork thing. My son helps me with a lot of the basic tasks, like the washing so I can get through them. The carers come and they’ll help wash and change me. Then my son does everything else.” (P11)  “I’ve actually accomplished more than I think I would have done because of opportunities that have  arisen. I am involved in a lot of stroke research. In 2021 I was awarded a lifetime achievement award, which  was amazing. I'm really proud of that. My favourite quote is ‘the possibilities are endless’. That is my  motivation and my hope. The stroke has done more for me than to me. (P12)  Well, I can work a phone to push the buttons because my arm is affected by the stroke, and using a fork and spoon. (P16)  No goals: 1,2,3,5,14  P1: No, I am still able to do everything I need to do which is good. (P1)  No, I'm quite happy with what I can do and that’s it. With my age as well, I’m limited in what I can do  anyway. I can’t do a lot anyway (P2)  No I don’t think so. It’s hard to say really. I just accepted what it is and who I am now and the support around me is enough.” (P5)  Well obviously I cannot walk, so I can’t do the garden anymore. Every night I would  prepare the evening meal, but I can’t do that now (P5)  Well, I go to a walking group. Okay, Mondays and Fridays. I think its like a mental health group. And it's nice going to walking with them to get a coffee afterwards and stuff. (P14)  “I’m 54, I’m happy with what I’ve got. I’ve got no goals in sight.” (P17) |

1. ***How to help the difficulty***

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| --- | --- | --- |
| **Area** | **Question** | **P1** |
| Factors that change hope  **Activities to help the difficult** | Are you aware of activities that may help? *Prompt: This could include both individually or as a group for people with stroke but also activities that you enjoy within the community.*  Have you experienced any of these activities? *Prompt: is there a reason for not considering this*  Is there things you can do to aid access? Or are their barriers that prevent you gaining access? | Goals  Community groups (P4;P6; P7;P9; P12) activities like dominos to help with concertation (P4) bowling (P6) social aspects of group nice (P7) helps avoid loneliness (P9) taking up opportunities (P12)  Betting gives a mood elevation (P8)  Staying active (P9; P15) going to gym (P15)  AI helps (P11)  Holiday helps fatigue (P12)  Listening to stories (P13)  Using pictures to aid communication (P15)  No goals  Haven’t looked for anything (P1; P2; P3:P5) or no activities that help (P17), not bothered because it will not change (P2), I know there is stuff out there to help but it is not for me (P3), I am house bound (P5).  Practice myself (P1) I must write things down (P14)  Goals: 4,6,7,8,9,10,11,12,13,15,16,17  “It’s good to do things that provide some sort of stimulation, nothing much is done after  leaving the hospital, so coming to community groups like this gives me some stimulation.  Not only physically but also mentally. (P4)  “Do you find that being around other people and joining in with activities like  dominoes helps your difficulty?” 4: “Yes, it helps with my concentration, because you have to be able to concentrate. (P4)  Well I go to the day centre twice a week on Mondays and Fridays.” Interviewer: “And what sort of things do you do there?” 4: “Well crafts and sometimes we go on trips like for meals and just about anywhere” (P4)  “I mean, the thing is here, they do bowling, which is nice, we all go for a meal, which is  nice. So, it does get you out doing things.” (P6)  First time coming to a community social group and enjoyed it. (P7)  Betting on the football is enjoyable and exciting to keep a high mood. (P8)  Stays as active as possible, playing games to activate the brain, social group to be involved and avoid loneliness. (P9)  Well, I wanted a bit more support on the computer, I’ve got the AI that helps me type the words. So it’s a good tool to have for people who have had stroke, a lot of people don’t know that you can use AI. But you do need a lot of help in general and I have a lot of people to get you through.” “I had 2 strokes, the first one I would walk after but after the second one I was put on medication” (P11)  “I try to keep myself as focused as possible by doing stuff like this [interviews]. It helps with my  motivation. I also make sure we get away somewhere warm and bright as a holiday because that just wipes  away all of my fatigue. I feel my fatigue going after living in this chronic mental fog over the winter. That’s a  part of the experience in managing the condition.” (P12)  I Listen to the people stories on YouTube. To see how they go about it and there is hope, so that's a good side of it. So, it's not all bad news. Yeah, I mean, there's some positive stories I like to listen to, more than the negative. It’s accepting that and understanding that. That is the people who people really know how it goes and they are probably proper friends. You want to reach out to them, and they probably want to reach out to you because you can share the same story and relate to them and they really, really empathize and understand what you go through? (P13)  Ive got a card for the for the gym. I went once to enrol and I’ve not been back since, thats on my bucket list to do. If a group like this could keep going then that’ll be a bonus because when i get tired of frustrated my speech doesn’t come out like the words I’m thinking of. At [name of NHS rehab facility] we has a support network but since then you’re left by yourself, like you’ve served your purpose and they’ve moved on. (P15)  “in hospital they used pictures (participant mimics pointing to pictures). People come into the house to do words. It's getting better now but it was hard work, very hard.(P16)  No goals: 1,2,3,5,14  P1: “I can’t say I’ve looked for anything apart from just practising myself. I don’t think they do anything here  for it anyway.(P1)  No I’m not bothered really. I don’t want to go to anything anyway because it won’t change.” (P2)  “I don’t think so, no. There’s nothing that I wanted to do in the past that I can’t do now. I can do  everything normally, I’m just sometimes affected by my balance….I’m very lazy, so I don’t go out of my way to do exercise or look for things. I see [name of friend] at the table doing all these exercises in his seat and reaching over. [name of friend] said it’s good for their balance but I can’t do all of them. Just the thought of them, I don’t wanna do it. I know there’s stuff out there to help, but it’s not for me.” (P3)  I don’t think so, no, no. I’m house bound as well, so other than the family and the grandkids, nothing” (P5)  I must write things down. I have to prepare myself, and be methodical. (P14)  “When you feel anxious, have you found anything that reduces that anxiety?”P17: “No.” (P17) |
| Factors that could change hope  **Cognitive strategy** | Is there any personal characteristics or attribute that have helped you previously? that you have help you keep going (i.e., determination, persistency)? | Goals  Persistence (P4) Refuse to accept (P4)  Determination (P4; P6; P7;P8;P9; P10; P12; P13; P16) keep doing things you previously done it is hard to stop that (P6)  wanted to prove myself that I could still do it [drive a car] (P10) I achieved them all (P12)  Motivated (P8; P13)  Committed (P13)  Religious (P11)  No Goals  Depends on mood some days wont do anything (P1) miserable so no nothing (P5)  Persistent (P1;P3)  Determined (P1;P2)  Being positive and grateful (P14)  Open minded (P17)  Goals: 4,6,7,8,9,10,11,12,13,15,16,17  “Persistence and determination yeah, and the fact that I refuse to accept it, I see it as a  challenged yes.” (P4)  : “I think so yeah. The thing is, careers seem to like me, and I do think to help them, like get things ready. When you have always done things yourself it’s hard to stop it; I get on well with people, they appreciate it. (P6)  *Always been very determined and this has not changed. (P7)*  *Even more determined and motivated than before. Always kept active and that is even more important as a core value now. (P8)*  Determined in anything in life, this is stronger since the stroke. (P9)  Interviewer: it seems like you come up with goals like you wanted to drive oh yeah you're very motivated to do that.P10: Oh yeah, everybody telling me to get an automatic because honestly [begins to get a bit emotional] wanted to prove that I could still do it. And I did. (P10)  Well I am a religious person (P11)  I think my previous career as a biology teacher has motivated me. I knew what we had learnt from trauma cases that I taught about the brain, so I saw an opportunity for me to be able to use my stroke as support for other people. It was just another opportunity. What was interesting was nobody had asked me what my desired outcomes were. I set all my own goals myself. The only one I didn’t achieve was riding a bicycle, but apart from that I achieved them all. My main goal at the moment is to further my research and do a major presentation at [prestigious stroke conferences].” (P12)  Yeah, I think motivation and real determination, commitment. Really the determination came from YouTube. I wanted to share. Yeah, umm, that's what gave me the empowerment really. You think you know not like cancer because people have more negativity around cancer than stroke. That’s something I thought of. (P13)  ’ve tried everything. I try to make the connection from my brain to my words but it takes a while. I can  picture the words. I’m determined. I’ve got the word in my head but I carry on till I get it right. It’s helpful if  [wife] says the word to me and then I think, that’s the one, and try to say it again.” (P16)  No goals: 1,2,3,5,14  “It depends what mood I’m in. Some days I don’t want to practise my writing at all. But then other days I would say that I am persistent and I will keep on going with it. But it fluctuates from day to day how persistent I am” (P1)  “It is determination with me. I won’t let things beat me, I’ll just have a go. I’ve always been determined even before my stroke. I like a challenge.” (P2)  I think I’m quite persistent as a person. Even after my fall, I just got up and got on with life. That’s just who I am before my stroke and now (P3)  “I’m miserable, so basically no! (P5)  Just positivity. I think I used to be quite depressed. But it's not good being depressed. I mean, so being grateful for what you have still, you know, it's all like, I think, choosing not to dwell on things you don't have is sometimes it's important to not do that, you know, um, because it does bring you down, doesn't it. (P14)  : “Can you identify any personal characteristics that may have helped with the anxiety?”P17: “Yeah I’m very open minded, not folding up and sitting in the corner.” |
| Factors that change hope  **Cognitive strategy** | Is there a different way to look on the difficulty or situation?  Are others with different views to a similar or the same experience useful?  Prompt is shared knowledge useful? | Goals  No (P4; P6)  People in worse situation and grateful (P8)  Never accepted that wont change (P9)  You have to accept the change (P10) need to be positive and pragmatic (P12)  No Goals  Good outlook, have to live with it (P1) take each day as it comes (P2) don’t see it as a problem wont hold me back (P3), I don’t see it a different way (P5), keep on going (P14), you have to get on with it (P17)  Goals: 4,6,7,8,9,10,11,12,13,15,16,17  No, no, no, I don’t think I am going to see it different, no (P4)  I don’t know, I don’t think so (P6)  Could not communicate an answer to this question and became slightly distressed, moved onto next question (P7)  Looking around there are other people worse. Feels lucky to be able to walk and talk which is motivating. (P8)  Never accepted it and that will never change. (P9)  What I found was my wife who had gone through [inaudible], I could do something today, tomorrow I can’t do it. If I did it yesterday, I know I can do it, it’s just a case of accepting that today its saying no. it’s like driving. When I drive, I have a steering spinner, obviously. I have it [inaudible], I always, sometimes in the morning, when its cold, my arm won’t grab it. My fingers won’t open up to grab, grab on to it. I have to sit in the car some mornings waiting for the car inside to warm up. Warm up my arm. Once my arm warms up it will go out. The thing I found. I do get mobility, (P10)  yes yes, its different now that I can do more now I can make a cup of tea and toast and all the simple things, they taught me that at the rehab home I was at. But I actually use a coffee machine its easier because its less steps. (P11)  I think if you aren’t a positive pragmatic person, that’s how I describe myself. I think that people look on the less bright side of life after a stroke find it hard because the improvement is very slow and I would say the improvement comes in steps rather than a gradient. If you recognise the improvements then it can keep you motivated, but I challenge anybody who says they cant improve (P12)  I don't know. One story I heard they were in the middle of nowhere, nowhere near family support. [Inaudible] I can resonate with that. Understand where she is coming from. I feel like that sometimes and others do so it probably normal to have those moments. (P13)  “I think they struggle with the problems and I empathise. I can see the hard work they have to put up With (P16)  No goals: 1,2,3,5,14,17  “ I think I have a good outlook on it because it’s something I have to live with. I’m not sure what other way to look at it really.” (P1)  I just take every day as it comes and that’s all that matters. (P2)  think that everybody has a different outlook on life and how they have been affected. But I’ve never seen my balance as a massive problem. It doesn't hold me back. There are things that I couldn’t do now but they are things I wouldn’t want to do anyway so I’m fine. I like the quiet life (P3)  No, I don’t see a different way (P5)  I keep on really, nothing in particular (P14)  Yeah. I’m very much like this is it and you’ve got to get on with this. Nothings going to change it. Some  people might wait for the operation, not do anything, not go anywhere. (P17) |
| Factors that could change hope  **Inspiration from others experience** | Do you know anyone close to you (e.g., partner, friend) that can help?  Are there others you admire that could offer you ideas of how to manage the difficulty? | Goals:  People here at group (P4; P7; P9)  Similar other who has lost their husband (P6) similar situation as me (P15)  Daughter (P6) Sister and son (P11) son (P16)  Physiotherapist (P8) Nurse (P11) Professor (P12)  None (P10)  No goals:  Family (P1), Daughter (P2)  No one (P3)  Friend who has diabetes and is an amputee (P5), a friend (P14)  Help with lifting heavy objectives (P17)  Goals: 4,6,7,8,9,10,11,12,13,15,16,17  4: “Well just coming here and having people that I can relate too, that’s my inspiration (P4)  Well I have a found who has just lost her husband, so we speak about things together which helps. It’s about how you hold yourself after something happens. (P6)  No, not really. Well, my daughter listens to me, and she takes me to every appointment  that I have got, but umm, no one really offers me ideas no (P6)  Not currently but possibly with the community social group. (P7)  Physiotherapist is helping with walking and is very positive. Painted the garden shed after lots of encouragement from the physiotherapist. (P8)  Social club is inspirational but no particular individuals.(P9)  Not from here. (P10)  well my sister comes up with ideas and my son does, but no one specifically. But you have to think outside the box.” (P11)  well it was the other way round to be honest. I would talk with a nurse there all about football and that was really good because it would get my mind going thinking of all the players names and things like that. That kind of thing though where people treat you like you are normal is a really important thing, it brings you back to the world (P11)  “I mean I was really lucky in 2009 I cold called the stroke research network and met professor [name of professor] and she has been my mentor ever since, she is wonderful. She has encouraged me, understood me, cultured my awareness on how things have changed and made me aware of the contributions I can make, I have been involved in some of her research (P12)  Talking about it has been a big help, but thats to get rid of all the pain. I wasn’t [social/open] before, but now I feel the more I meet people from the same situation makes it easier. And if i can help somebody else that’s a bonus too. When it first happens you think you’re the only person in the world who this happens too, but after a while you start to [loses thought process]. (P15)  There was a chap at [name of NHS rehab facility] who used to come in in a wheel chair and eventually started walking but took his time. After a while no matter what he did, it wouldn’t see any amount of progress because he was in that mindset that it couldn’t get any better and I think that was one of the negatives of [name of NHS rehab facility] as no matter, as we are not as able bodies as we used to be, we could be a lot worse. To see someone who can do something but doesn’t, it’s comes to a point where if you want to improve, you have to work yourself, you have to pull your finger out or if you have that negative outlook, why did you come here? There are plenty of people waiting to come here who want to work but cant. (P!5)  “My son comes. [Wife explains that their son tries to rephrase sentences to help the participant].It’s just hard work when I try to speak and have a conversation. It’s hard work (P16)  No goals: 1,2,3,5,14  “My family. They are a good support system” (P1)  - “I’m on my own, but my daughter is really good. She gives me help when I need it. She’s my rock” (P2)  “I don’t know anybody really. I’m happy as I am and that’s that. (P3)  I have a friend, but he lives away from Birmingham, he has diabetes and both legs amputee above the knee, so I admire him (P5)  I’ve got a friend and she sorts me out really. (P14)  “It’s just heavy lifting but I have help for that.” (P17) |

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| Topic | Goal group | No goal group | Group differences |
| Does the difficulty change over time? | Three individuals identified it as getting worse over time (P4;P6; P10). For P10 this was notable since pandemic. Two individuals said it was the same over time unchanged(P8;P9). One individual identified the difficulty as improving over time (P16).  Six individuals focused on what you must do to manage. Including coping with the effects over time (P8), have to work hard to improve situation (P9) or manage your situation (P11) had to empower myself , have a routine, write things down to cope (P13), your brain takes longer but you can do it (P15) and they have managed to understand it and control it (P12) | Three individuals identified no change – when writing it take energy and gets worse as more is done (P1), know what to expect (P2), got used to the changes (P3). One individual stated that you need to make lifestyle changes (P17). | More of the no goal group identified no change over time (P1;P2;P3, 3/6 = 50%). Whereas some of the goal group identified a deterioration over time (P4;P6; P10, 3/11 = 27%). Six individuals in the goal group (P8;P9; P11;P12;P13;P15, 6/11 = 55%) and one individual in the no goal group (P17, 1/6 = 17%) across the group focused on being able to manage the situation. |
| The impact of the difficulty on important roles, identities or groups associated with. | Six individuals highlighted the importance of other family members (P4; P7;P8; P10; P12). Four were worried about the impact on the others as carers (P4;P7; P8; P10;P12).  Unseen nature family don’t appreciate it (P4) others don’t appreciate the struggle and suffering (P13).  Dependent on family (P4), family have to act as carers which adds stress (P7), wife as carer and worried about stress on her (P8), supportive son (P10), more dependent on wife around the house (P12)  Loss of contact only see daughter (P6) continuing to live independently regardless family worried about an accident occurring (P9), reduction in contact (since COVID) (P10), cannot drive anymore (P11) friends don’t come to see you (P15) | Four individuals identified no impact (P1; P2; P3; P17). One stated as the reason that they were doing what could be done before (P2).  apart from stroke group doesn’t go out (P3)  Prevents bowls (P5)  just frustrating (P1)  More cautious about gardening and what is taken on (P2)  Daughter supports (P2) | The main group differences was the goal group highlighted the reliance and importance of family members that provide care (P4; P7; P8; P10; P12, 5/11 = 45). The no goal group identified no impact on their roles (P1; P2; P3; P17, 4/6 = 66%). This could be because they don’t go out (P3) or what is prevented is limited e.g., bowls (P5). |
| Impact of the difficulty on meaningful relationships | No change in relationship to family (P6; P12; P15)  Sees family, children, grandchildren more (P8)  Looked to make more friendships as struggle with loneliness (P9) have arranged to get friends to take them out (P11)  Don’t see family as much (P11) | No change (P1,P2, P5, P14, P17) | Across the goal group (P6;P12;P15, 3/11 = 27%) and most (P1; P2;P5; P14; P17, 4/6 = 83%) non goal group identified no change in meaningful relationships. The goals group identified having more contact with family (P8) looking to make more friendships (P9), having friends take them out more (P11). |
| Impact of the difficulty on tasks or accomplishments | Yes (P6;P7; P15; P9; P10:P11; P16)  basic tasks and support would be valued (P6)  would like to walk again (P7) would like to do the half marathon and full marathon but it will take longer (P15)  limits gardening and cannot do to much, only can do the washing up cannot do ballroom dancing (P9) limits eating, reading and being able to concentrate (P11) working a phone is possible and using a fork and spoon is possible (P16)  No (P12) being able to do more because of opportunities | No (P1;P2;P5; P17)  Happy with what can be done (P1;P2) or they have (P17) and accepted it (P5) | The goal group identified that the difficulty had impacted on tasks and accomplishments more (P6;P7; P15; P9; P10:P11; P16, 7/11 = 64%). The no goal group identified no impact most often No (P1;P2;P5; P17, 4/6 = 66%) |
| Activities that can help | Community groups (P4;P6; P7;P9; P12) activities like dominos to help with concertation (P4) bowling (P6) social aspects of group nice (P7) helps avoid loneliness (P9) taking up opportunities (P12)  Betting gives a mood elevation (P8)  Staying active (P9; P15) going to gym (P15)  AI helps (P11)  Holiday helps fatigue (P12)  Listening to stories (P13)  Using pictures to aid communication (P15) | Haven’t looked for anything (P1; P2; P3:P5) or no activities that help (P17), not bothered because it will not change (P2), I know there is stuff out there to help but it is not for me (P3), I am house bound (P5).  Practice myself (P1) I must write things down (P14) | The goals group more often identified aspects which helped. This included Community groups most often (P4;P6; P7;P9; P12, 5/11 = 45%) activities like dominos to help with concertation (P4) bowling (P6), or staying active (P9; P15). The no goals group identified not looking for activities to help (P1;P2; P3; P5, 4/6 = 66%) |
| Characteristics that are associated with themself | Persistence (P4) Refuse to accept (P4) keep doing things you previously done it is hard to stop that (P6)  Determination (P4; P6; P7;P8;P9; P10; P12; P13; P16)  wanted to prove myself that I could still do it [drive a car] (P10) I achieved them all (P12)  Motivated (P8; P13)  Committed (P13)  Religious (P11) | Depends on mood some days wont do anything (P1) miserable so no nothing (P5)  Persistent (P1;P3)  Determined (P1;P2)  Being positive and grateful (P14)  Open minded (P17) | The most consistent termed used to describe peoples characteristic was determination, this was more frequent in the goals groups (P6; P7;P8;P9; P10; P12; P13; P16; 8/11 = 72%) than the no goals group (P1;P2; 2/6 = 33%). Two from both the goal group (P4;P6; 2/11 = 18%) and no goal group (P1; P3, 2/6 = 33%) identified being persistent. |
| A different way to look at or consider the situation | No (P4; P6)  Never accepted that wont change (P9)  You have to accept the change (P10) People in worse situation and grateful (P8)  ) need to be positive and pragmatic (P12) | Good outlook, have to live with it (P1) take each day as it comes (P2) don’t see it as a problem wont hold me back (P3), I don’t see it a different way (P5), keep on going (P14), you have to get on with it (P17) | Mixed responses were identified in the goal group. Three (P4;P6;P9, 3/11 = 27%) identified that they did not look at the situation differently (P4;P6) or never accepted that change is not possible (P9). Whilst three others identified accepting the situation (P10), being grateful the situation is not worse (P8) and being positive and pragmatic (P12).  The narrative from the no goals group focused on the need of continuation (P1;P2;P14;P17, 4/6 = 66%). In their words this was to take each day as it comes (P2) or live with it (P1) or get on with it (P17), keep on going (P14),not let it hold you back. |
| Others that can help | People here at group (P4; P7; P9)  Similar other who has lost their husband (P6) similar situation as me (P15)  Daughter (P6) Sister and son (P11) son (P16)  Physiotherapist (P8) Nurse (P11) Professor (P12)  None (P10) | Family (P1), Daughter (P2)  No one (P3)  Friend who has diabetes and is an amputee (P5), a friend (P14)  Help with lifting heavy objectives (P17) | The most consistent response for the goal group (P6;P11; P16. , 3/11 = 27%) and non goal group (P1; P2, 2/6 = 33%) was the support identified from a family member. The goal group (P8; P11; P12, 2/11 = 27%) also identified a health care professional that helped them. |

Patient perception of the interviews

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| **Question** | **Response by each group** |
| Perceptions of the intervention | ***Goal group***  Valuable social interaction (P4), valuable to ask questions and help people who are reserved or quiet (P8), identify problems (P9),  Really worthwhile (P12), pleasant (P16), positive because it allows the person to talk (P15) and good questions (P13)  Helps others (P6;P10)  People are nice at University (P11)  Example quote  *No, I think they were very good question. They are all part and parcel of what has happened, nothing happened untoward, nothing that I wasn’t expecting*. (P13)  Quotes  Good social interactions (P4)  Well as I say, if it helps other people by talking about my problems, then it’s good (P6)  *Big help to anybody, very good to ask questions and help people who are quiet and reserved.* (P8)  I, don’t mind doing anything that helps others (P10)  Would you like any of this to change? The conversations? The questions?  Patient 5:00 [shakes head no] (P10)  *No problems, I told you if I had any problems, I would tell you (P9)*  yeah its ok you are nice people from the university, I’m used to university people (P11)  I think it’s really worthwhile (P12)  No, I think they were very good question. They are all part and parcel of what has happened, nothing happened untoward, nothing that I wasn’t expecting. (P13)  When you all came in and sat down, I thought you would just be here to listen. And when they said you are going to pair off and chat, I was a little [shakes hands]. But, uh, I’ve enjoyed it because it gives you a massive ice breaker. Don’t have to worry about thinking “he’s a clown he is”, that’s out of my head I’m not fussed about that. Just as long as I don't from waffle on that much, you know. So very positive (P15)  Some of the questions made me think and bring things back to that I haven’t spoken about in a long time. So that’s another bonus isn’t it. I’ll sleep like a baby when I get home (P15)  It was pleasant (P16)  ***No goal group***  Helpful and useful (P1; P5), good and positive (P17) and fine (P3).  Can help others (P2; P5) for the research (P3)  *Example quote*  Yeah it was ok. If it helps other people then that’s what I like. I know it won’t help me much but if my answers helps others and research then it’s good. (P2)  Quotes  I think it was very helpful and useful. (P1)  Was there anything that stood out about it? Can you explain what that was? P1: The structure of the questions and how they were delivered came across well. (P1)  Yeah it was ok. If it helps other people then that’s what I like. I know it won’t help me much but if my answers helps others and research then it’s good. (P2)  Not for me [no benefits] because no one can do anything for me. But if I can help others by talking then that’s good. (P2)  None, it was all fine (P3)  It’s for the research I guess. (P3)  Well, actually it has been helpful (P5) I am just pleased that it may help others (P5)  It was good. Positive (P17) |
| If it was considered beneficial | **Goal group**  Talk about things that haven’t been talked about since the stroke (P4), talking about feelings (P6;P9) and expressing view (P9;P16), value in the question (P8; P10). In particular P11 valued there being no interruption of answers and P12 valued the questions that were gentle when considering personal circumstances. Initially apprehensive, P15 enjoyed the interaction and described it as an ‘icebreaker’. Value in revealing the information so other people will know more because of what is asked (P6)  Example quotes  *Well I’m able to talk about things in a way that I haven’t really been able to since the stroke, because no one tends to really ask me , they just look at the physically difficulty and think that’s it*. (P4)  you let me take my time and let me answer the questions, I told you some of the problems I had during the interview (P11)  Quotes  *Interviewer*: “Was there anything that stood out to you about this intervention, and can you explain this to me please?”  P4: “*Well I’m able to talk about things in a way that I haven’t really been able to since the stroke, because no one tends to really ask me , they just look at the physically difficulty and think that’s it*.” (P4)  Well it’s good that you come round and ask, because other people will know more if we talk about our problems (P6)  Yes, helping other people .” (P6)  I don’t think anything was not so good, because the questions you have asked, I have been able to answer (P6)  People sometimes just want to be asked about how they are feeling (P6)  Good to be asked the questions (P8)  *I Just like answering questions and talking to people… express my views (P9)*  think what all hospitals need to do is, obviously this [inaudible] hospital. You need to support on the ward [inaudible] because some of them struggle. [inaudible] to contact family members. [inaudible] I think that would be a good idea. (P10)  I, don’t mind doing anything that helps others (P10)  well you’ve asked me a lot of questions and you haven’t interrupted me so thank you very much (P11)  well its quite good, you let me take my time and let me answer the questions, I told you some of the problems I had during the interview (P11)  P11: well its been really nice having a chat with you today.”  Interviewer: “what would you say that was good about it?”  P11: “because you listened when I was talking about my past experiences (P11)  I think its quite interesting actually, what stood out to me is that its not looking at the traditional things and really focusing on gaols. I have real problems with physiotherapy goal setting. I found it difficult to set goals while in hospital only when I got home I could start doing that (P12)  I think it’s really important to gently approach the topic of relationships with family, as you did well. Especially in terms of marital relationships, so many things change post stroke and that can be hard to discuss (P12)  And when they said you are going to pair off and chat, I was a little [shakes hands]. But, uh, I’ve enjoyed it because it gives you a massive ice breaker. (P15)  No problems at all. I think it was good because I’m speaking to people. I’m not just sitting in the house (P16)  I: “Do you feel like you have benefitted from this intervention?”  P16: “Yeah it’s alright. It wakes me up.” (P16)  ***No goal group***  Talking to others helps (P1;P3), talking about challenges helps (P2) or sharing problems helps (P5), having a goal to work towards is important (P17). Provided an escape for a moment (P5).  Value in being part of research (P3)  Example quote  It helps you to recognise what your abilities and struggles are and what your goals could be if you wanted to improve. (P1)  Quotes  Just talking, it does help. Someone different too, talking to other people is really good (P1)  Yeah that would definitely be helpful. It helps you to recognise what your abilities and struggles are and what your goals could be if you wanted to improve. Just talking, instead of going straight into treatment. It feels more personal and directed. (P1)  It was good to have a chat and talk through things again with someone different. I think that is always beneficial even if it doesn't change much. It’s nice that people come and chat to us. (P1)  talking about it can be helpful. Talking about challenges helps. Anything helps. (P2)  It’s always good to have a chat. I like talking. Any intervention like this is alright. (P3)  Nothings changed. It’s just something that’s happened. It’s for the research I guess. (P3)  Interviewer: “Helpful? How has it been helpful?” P5: “Well it has taken me away and gave me a little escape for a few minutes” (P5)  “Well I’m sharing the problems I’ve got with you, whether that will help anybody else, I don’t know” (P5)  Yeah. It gives people something to work towards, a goal. So mentally you’re not just flat (P17) |
| Use in practice and on placements | Goals group  “I think it would be really useful as a training exercise for students, to develop emotional intelligence and the way to communicate with patients. I think it’s really important to recognise that the patients you are with really aren’t as they once were because personalities do change (P12)  Yeah, absolutely yeah (P13)  Oh yeah, it could do. I’ll have a chat (P16) |
| Value in hospital | Goals group  Important because people feel depressed in hospital (P4; P6) people value being given social support (P4) or asked how they are feeling (P6).It builds familiarity and if this was provided on the ward would be remembered (P11). Value may not be straight away but before you leave hospital to feel like you are not on your own (P15).  Not much value as you need more time to comes to terms with what has happened (P12)  Example quote  *Yes, it’s [MEAH] very important. I think in hospital they refused to see the fact that I was depressed. I lost my job, and my independence and people fail to realise that there are more than the physical effects. I think they should provide more social support in practice* (P4)  Quotes  Yes, it’s very important.” (P4)  Yes, I think in hospital they refused to see the fact that I was depressed. I lost my job, and my independence and people fail to realise that there are more than the physical effects. I think they should provide more social support in practice (P4)  Interviewer: Do you think that these question that I have asked you will be valuable to ask patients in hospital who have maybe had a stroke?”  P6: “Yes, yes definitely.” …Interviewer: “Can I ask you why please?”  6: “Because, the thing is, they would be feeling quite low wouldn’t they. I felt low, and I was lucky, there will be lots of people worse than me. But when they know that people are worse than they are it will give them confidence that they will be okay. People sometimes just want to be asked about how they are feeling (P6)  yeah you could do this on the ward I was on a ward with lots of people with brain difficulty at different levels. Its good to speak to people more than just one time though to get to know them it helps build familiarity as well (P11)…Interviewer “do you think the questions we have asked today would be good in building trust?”  P11: “yes I guess so, if I was speaking to you two on the ward and you came up to me I would remember who you were. Yeah I think the questions you asked were good.”   (P11)  don’t think it’s of much use in hospital as you haven’t had enough time or your brain might not be in the position where it has the capacity to fully understand the questions because that changes the way you can respond to question (P12)  think this would be a good thing. I wouldn’t say straight after surgery but at some point before you leave hospital. Because obviously you’re in there for the treatment and they've done their job, so it's next. But if you could have something like this, so it made us think before we even leave, you know you're not on your own, three are other people like you and it could be this bad, at this stage, it makes you appreciate before you've left rather than having that break. And then trying to get the cogs kicking in again. It starts you on that wavelength of thinking; same you, different version. If you could have that before you actually left, that would be [inaudible]  (P15)  Yeah. Cause [name of rehab facility] you’ve had that space away where you felt sorry for yourself, moped, and did things like that. That next level with [name of rehab facility] is the next step up, rather than the unknown. When you first turn up, you’re in a room full of strangers, you don’t know who’s worse, who’s better, so you get a lot of apprehension. If you break that scenario before you got there, it does the same as you are doing now. You will all have your issues, it’s getting a better mind frame, frame of mind before you get there. So, we could either just leave it or just before [name of rehab facility], a bridge between the pair. (P15)  ***No goals***  Yes there is value (P5; P17). Some questions irrelevant for me but the value can be seen and the structure was good (P1). Value may depend on who the person is and if they want to talk (P2;P3)  *Example quote*  Individuals are different from each other. So what might be good for one person might not work for another. I don’t think this would work for me. (P3)  Quotes  I think some questions were irrelevant for me personally, but they could be applicable for others so I think it was structured well. (P1)  Yeah at the start it could be helpful with the education around strokes so you understand what is going on and can talk through goals from the beginning. (P1)  Yeah it could be when you first go to hospital in the early stages. Some people are worse and others and talking about it can be helpful. Talking about challenges helps. Anything helps. (P2)  It might be but it depends on who they are as a person and if they want to answer and talk about it. (P2)  Individuals are different from each other. So what might be good for one person might not work for another. I don’t think this would work for me. (P3)  No because it’s only after the stroke that you actually grasp what’s happened. Understanding yourself comes from the experience of going through it (P3)  Umm, yes, but I would hope that nobody else would have this (P5)  Yeah, definitely. Just communication is key (P17) |
| Duration of intervention and number of questions asked | Goals  Time works and happy with the duration and number of questions(P4;P6;P9;P10:P11:P12:P15)  Could go longer (P4) would pass the question if I wasn’t happy (P9)  Example  Quotes  “The length of time is fine, you could go on longer if you like, no problem.” (P4)  Were you happy with the number of questions? P6: yes, yes  Interviewer: “What about the length of time of our intervention?”  P6: “It was okay.”  *“No problem because I would pass the questions if I wasn’t happy”  (P9)*  Interviewer: Considering the questions we’ve asked, are you happy with the number of questions I’ve asked you today?  Patient 10 [nods]  Was the length of time we spent appropriate? Was it alright?  Patient 4:48 Yeah yeah. (P10)  “yes no problem at all, they were nice clear and precise.” (P11)  @i’m used to being online so it doesn’t affect me so much but some patients might get bored or feel that it’s a bit intrusive, but others will maybe embrace it. I think it’s more interesting when the intervention happens I think this is useful when the patient has had some time, when they are probably as home or back in the community (P12)  yes I thought you were both really good you were really tolerant and you listened while I spoke.” (P12)  Yes, yeah, fine yeah. Reasonable. They weren’t complicated, no abbreviations I didn’t understand, no jargon. (P13)  As long as you have got the time yourself [interviewer]. I’ve got no issues because you are not forcing me to answer, you haven’t my arm up my back as far as I know [laughter]. If you don’t want to answer, as you said at the start, you don’t have to answer. I’m doing a load of waffling anyway. That’s no issue with the number of questions. (P15)  No it’s alright, no problem.”  ***No goals***  Fine (P1;P3;P5).  For me I think it was fine. Some questions didn’t really apply to me but I can see how it would help others. (P1)  All fine. (P3)  Yes, it was all fine (P5) |
| Role in treating neurological illness | ***Goals***  Yes (P4;P11;P10;P12;P13 P16), useful (P6; P10), beneficial (P12), brilliant (P16), important (P4; P11)  Example quote  I think anything that get people to open up about a conversation about their life by people with experience in stroke is beneficial. I hope the intervention is also used as a tool to help open up conversations for those people that have lost all their confidence (P12  Quotes  “Yes, it’s very important.”(P4)  “I think other people would find it useful, wouldn’t they?” (P6)  Would you consider these questions to be valuable to people in hospitals with similar conditions?  Patient 3:37 …yes. But. You mean brain injuries?  Interviewer 3:52 Yeah, yeah. So with stoke patients. So just having a chat with, about difficulties, their feeling about it. Asking about how its affected them (P10)  Oh yes its very good, its important to have a chat it gets your brain going.” (P11)  I think anything that get people to open up about a conversation about their life by people with experience in stroke is beneficial. I hope the intervention is also used as a tool to help open up conversations for those people that have lost all their confidence (P12)  Yeah, absolutely. Yeah (P13)  Additional questions could be asked however,….did you feel that anything that's lacking in your life like. Do you think you could have had more access to the social services. Your GP, how accessible is that? (P13)  Oh yeah, brilliant. It helps people. It depends on how their brain works though (P16)  ***No goals***  Yes (P1; P2; P5), help with feelings (P1; P5).  Example quote  Yes, it would be good to adapt it to all people with illnesses, it will help people to talk about how they feel (P5)  Quotes  Yeah it will help people to understand themself and accept what has happened to them. The processing of what has happened, instead of suppressing feelings (P1)  Yes it’s always good to talk and some people need it more than others. (P2)  Yes, it would be good to adapt it to all people with illnesses, it will help people to talk about how they feel (P5) |
| Could the intervention be used more widely for Pts more widely | ***Goals***  Yes (P4;P6;P9;P11;P12). Cant answer the question as not sure(P16)  Example quote  I think it’s perfect with physio because patients love physios, because you are the face of care and are therefore more likely to have a conversation with you and be more honest with you (P12)  Quotes  4: “Oh yes definitely.”  “Yes, yes.” (P6)  *Depends on the individual, some people don’t like answering questions  (P9)*  “yes.”   (P11)  I think it’s perfect with physio because patients love physios, because you are the face of care and are therefore more likely to have a conversation with you and be more honest with you (P12)  “I can’t answer that one because it’s the brain isn’t it. It’s not physical so I’m not sure.” (P16)  ***No goals***  *Yes (P1;P2;P5;P17).*  quotes  Yeah to help people to identify their struggles and goals. (P1)  It helps understand the goals and problems before. (P2)  I think so (P5)  Yeah you tend to get people mobile again and spend a lot of time with us.” (P17) |
| Other comments | I think you might have to change that question about age, maybe it would be better to ask what age range someone is in.” (P12) |

**Student responses**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Theme | Sub-theme | Code | Example | Participant |
| Value of the research placement | Value of research placement | Experience of the process | Write up experience and going through the research process has value (P1:P2:P4:P5)  Example quote  *normally on placement you just perform interventions and don’t really consider the process behind them. I don’t really think I would have ever explored this post university if. I hadn’t had the opportunity now* (P2)  *It's a bit different than a traditional placement that people I think expect to have. But it feels very involved in the development of the area of study* (P5)  Quote  I think going into this research and going through things like writing up methods for a paper is really beneficial, because even though we have had a research module before, I don’t feel like we have fully gone through how to write a research paper in this much depth. Looking at frameworks and what to include is a good skill to gain for things like our dissertation and other projects. We wouldn’t have got those skills on a clinical placement (P1)  Yeah, so I think it’s been a positive experience for me so far (P2)  But I think it’s taught me a lot of skills that I wouldn’t get from a clinical placement. (P2)  I think there are definitely benefits, it’s good to see things from a research perspective, where normally on placement you just perform interventions and don’t really consider the process behind them. I don’t really think I would have ever explored this post university if. I hadn’t had the opportunity now (P2)  The placement has been really good as it has given me the opportunity to participate in conducting research. My perception of research has changed since starting the placement in a positive way. I also think that I have gained many transferable skills that I will be able to use when completing my dissertation (P4)  now have a better understanding on what research in physiotherapy looks like and as I previously mentioned it will benefit me in my dissertation (P4)  My experience has been quite interesting. It's a bit different than a traditional placement that people I think expect to have. But it feels very involved in the development of the area of study, I guess. So just incorporating research. And as research progresses to help apply these, these thoughts, or theories into practice (P5)  I think starting up rule was good is very simple, straightforward. It was good to kind of try to get your head around it very quickly. And have somebody that's obviously very experienced and is flexible and understandable to what our capabilities are, and try to challenge them, but also accommodate them, even though it's their project. (P5)  And I guess what's also good is that there's not too much oversight. They trust us enough to get the work done. And there's no kind of like micromanaging of it. I guess, about like the negative side, I think it's just more contact time I suppose. (P5) |  |
|  | Alternative placement consideration | Expectations needed | Expectations of what is needed for good grades (P1)  Different to other placements (P2)  Independence valuable (P4)  Exposure to research (P5)  Quote  For the placement as a whole, I think the expectations of what we are meant to be doing could be clearer because I am finding that I’m not sure if I am doing enough work to achieve good grades or not, because of the freedom and nature of the placement.” (P1)  I wasn’t sure what to expect to start with just because it’s completely different to any other placement I’ve had before (P2)  In comparison to other placements this placement offers a lot more independence. I have enjoyed organising my own time and having more freedom with where I want to take my work and what I want to focus on (P4)  I think benefit wise is just kind of exposing ourselves to, to research. at an earlier stage, instead of just waiting until you're done. Or you're training, you're either put on, like in the field into work, and then you kind of decide to go back into research, but you don't, you have no clue how to get around it. So, today's how to, I think introduce it to you and in like a safe environment. So that you're not worried that this is like a grade, or this is your job, or whatever it is, like, it's, it's nice and easy. And it prepares you to like, I think it's preparing us to like write or just like our own pieces of research or work that we're going to submit as well. So then, I think there's there is added benefit, even if you don't like it, necessarily, it's not too taxing, and just get over and done with and move on to the next placement. (P5) |  |
|  |  | Quieter environment | Location for assessments could be quieter (P3;P6)  Quote  ... I think on the more practical side to be honest and just having a more private environment will definitely improve what we did in particular. I saw difficulty understanding patients and often someone may be quiet, or speech might not be completely clear. Having, you know, a quieter environment is easier (P3)  I think, on more practical side, to be honest, just having a more private environment will improve, especially as it was difficulty understanding patients. Having, a quieter environment is easier, and it lends for a bit more of a confidential environment in which we weren't really a confidential environment. What we would transcribe it would be confidential, but the actual environment itself isn't confidential, and talking about potentially sensitive topics.  (P6) |  |
|  |  | Group working valuable | Quote  I have really enjoyed the placement so far it’s been quite a new experience for me. I have found that the group has been really helpful and that we all have worked very well together so far (Q4) |  |
| Value of the MEAH tool | Insight from experience | Understanding experience of people who have had a stroke | Understanding experience that an individual with stroke has or what life is like (P1;P2;P3:P6), advance understanding in a new way (P4) provided a deeper understanding of life with stroke (P6)  Quotes  I think this experience has been quite helpful to gain an insight into the different experiences stroke patients have had… it was nice to see the variety instead of just speaking to one patient or patients with the same experiences and challenges(P1)  I think, the reward that I got from speaking to the stroke patients, so normally on placement, it’s rewarding but usually on a more functional aspect. It was nice to have conversations about what the patients were struggling with and how this was having an aspect on other aspects of their life. That’s something that I have never really had time to explore before, because we often don’t have the time in hospital settings and I think being able to use the MEAH gave me a structure to the interview, but also enabled me to have some creativity and freedom during the interview in relation to the responses. (P2)  Well, I found it overall quite insightful on the day… during the interviews and just getting an understanding and appreciation for what life is like. I think readapting to life really… But them having the stroke and then that that knowledge of that importance has been impacted, you know, affecting the rest of their life and how they approach the rest of life. (P3)  I find that patient interaction makes an enormous difference and I think these sorts of things can be important for students. Especially say the brand-new undergraduates, thinking about or gaining appreciation for what it's like someone else, you know, that different perspective from their own, which again is only a positive thing (P3)  I have had some previous placement experience on a stroke ward, so it’s been really nice for me to advance my understanding on stroke in a new way (P4)  I also think I have benefitted from conversations with patients and learnt a lot from them too (P4)  think being able to still have contact with patients, was, I think there's something that stood out, you kind of think, being in research, a research project, you kind of sit behind a computer, or you just like reading a lot. But so, it's nice to actually still have contact with patients, like real patients, and getting that kind of experience of interacting with these individuals (P4)  I found it overall quite insightful, on the day during the interviews, just getting an understanding and appreciation for what life is like, I think re adapting to life really. And, and how you mentally change. (P6) |  |
|  |  | Understanding the individuals psycho-emotional response to the stroke | Experience and feelings or emotional aspects of rehabilitation (P1;P2;P3) focus rather than mobility and physical focus (P1)  Importance and value of hope (P3) and how hope is accessed (P6)  Allowed the student to listen and explore (P5)  Some people had a lot of experiences to share (P5)  Example quote  *using the MEAH intervention I’ve realised that the emotional aspects sometimes have the biggest impact on patients, and I think that it’s easy from a physio perspective to just see physical and functional difficulties* (P2)  *they saw that as a positive rather than a negative where it's very easy to look at these life changing events that can also be quite debilitating....But they still take positives from that when it's very easy to get lost in the negatives and self-pity, those sorts of things. I think it's that sense of hope and ... they're like being thankful for what they have. I think that stood out for me in particular* (P3)  But how they still take that and find the positives when it's very easy to get lost in the negatives and self-pity, I think this that sort of feeling of their feeling of hope. (P6)  Quote  We get to understand their experience and feelings more rather than being there to help with their mobility or physical rehabilitation. We can look into the mental side of how they have been affected.” (P1)  And I think it’s been really positive to see the more mental effects that a illness can have on a patient. After speaking with stroke patients through using the MEAH intervention I’ve realised that the emotional aspects sometimes have the biggest impact on patients, and I think that it’s easy from a physio perspective to just see physical and functional difficulties. (P2)  Often patients would state that often after having something like a stroke, the mental and emotional aspect of it is often ignored, which is obviously hard to hear from a practitioner viewpoint. So, I think the social and emotional impacts of a long-term health condition should be considered (P2)  It's been much more recent and managing those sorts of feelings in the moment, you know, sort of in the days following a stroke. (P3)  just how sort of surviving that situation really stood out for me, how they saw that as a positive rather than a negative where it's very easy to look at these life changing events that can also be quite debilitating. And you know, often they can leave you disabled and there's nothing you can do about it unfortunately sometimes. But they still take positives from that when it's very easy to get lost in the negatives and self-pity, those sorts of things. I think it's that sense of hope and ... they're like being thankful for what they have. I think that stood out for me in particular (P3)  think, you know, therapists, like students, should keep their mind open, try to keep their appreciation for someone else's perspective. Also, different departments, you know, like threads of hope and these sorts of things and it's not solely restricted to stroke or neurological conditions, you know. Trauma or whatever it might be, those things are life changing, mentally it's a big hurdle, big mountains to climb over. But again, focusing on the questions we went through on the MEAH interview, like feelings of hope and you know talking about the emotions and being aware of the emotions. Again, it's just useful for whatever department and whatever area of work you're in. If that's even a physio that could be a GP and that sort of work (P3)  Because in my limited experience, it seemed like it was hard to narrow back into the main question that we were asking. Yeah. Especially if they have such greater experiences, like many years of it, like they have all this experience of dealing with their, like injury or recovery. So, they go down, they can they wander off into different avenues. Or, but so it's hard to say. Yeah, it was a question. Yeah. I think for what we were intended to do, or our goals were, I think it was it was good. Because, like, it just allowed us to listen and try to explore people's experiences with those with those with their answers. (P5)  Often what I've seen so far, most of my experience has all been acute issues based. It's been much more recent. And managing those feelings in the moment in the days following a stroke, but I've never really sat down and had a conversation with someone who, several years down the line, if it's like over 15 years almost, down the line since that struggle, how life is like, when you left the hospital circuit of the health care and the frequent check-ups. Just seeing how the personalities have been strengthened from it, and how they've say, almost thrived. They're very conscious about their health and about how well they're doing physically, and they're taking a lot of care. And then that that knowledge of that importance has then impacted, you know, the rest of their life and how they approach the rest of their life as well. I was that found quite nice, quite motivating if anything else, it was very insightful, to be honest. (P6)  I think personalities change, and how they thrive in that situation, I think that that really stood out for me. How they saw that as a positive, rather negative where it's very easy to to look at these. It's a life changing event and they can also be quite debilitating, and there's nothing you can do about it, unfortunately, sometimes. But how they still take that and find the positives when it's very easy to get lost in the negatives and self-pity, I think this that sort of feeling of their feeling of hope. Them being thankful for what they have, I think was that stood up for me, being appreciative of what you have not rather than what you don't have. I thought was just, it was nice. I didn't have any expectations going into it, but it was nice having a conversation about something like that. (P6)  just getting an understanding and appreciation for what life is like, I think re adapting to life really. And, and how you mentally change. (P6) | P1;P2;P3;P5;P6 |
|  |  | Linking goal setting to hope | Quotes  Some had quite positive outlooks, whereas others who had maybe been living post stroke for many years didn’t have much hope or positive feelings that things were gonna change. It was also interesting to see how this linked in with goal setting or lack of with these particular patients (P1)  it's quite insightful really and I've just seen how the person has... or the people from people I spoke to, how their personalities have been sort of quite strengthened from there and how… they almost thrived in it, you know? (P3)  considering especially in quite a potentially negative environment, which could be quite easily a negative environment for patients. We're not forcing it as well because obviously there are plenty of questions and the patient can take them wherever they want. They know the answers, they are not restricted.  But you know, almost open their minds to trying to think positively without forcing it. Um, which I think is quite a good thing.   (P3) | P1:P3 |
|  |  | Collaborative approach to goal setting | How to consider identifying goals (P1)  Example quote  *As physios, we normally go in with the goal of getting patients independent, walking, talking etc. But the patient might have other goals that we wouldn’t think of and a tool like the MEAH could help us identify that* (P1)  Quotes  I think the MEAH can be applicable for students to use with patients. Talking through what the patient finds challenging, what goals they have, and what they want to get back to is really helpful before planning their rehab. As physios, we normally go in with the goal of getting patients independent, walking, talking etc. But the patient might have other goals that we wouldn’t think of and a tool like the MEAH could help us identify that. It gives us a direction of where to go with our rehab and what to focus on so that the patient feels like it is a collaborative intervention, instead of us telling them what exercises to do (P1) | P1 |
|  | Using the tool | Structure and content | Quotes  I think having the actual MEAH tool was quite good because it meant that we had a structure to go from and it felt more like a guided conversation rather than us just asking questions (P1)  I found them useful to go over things a little bit as they get a bit more in-depth. They were very closely related what we're asking anyway, which would lead to very similar conversations, but then you get a little bits here and there that are slightly different. They might go into something else a bit more. Often, the participant would go off on a little tangent on what they meant on one thing, and that's great, and then you move on. But then it gives another opportunity to come back to that and this time it might go on different tangent, which was great again. (P6)  I think they get the students or the practitioner, and the patient, thinking a bit more about what they have. Often we rather promote positivity than negativity and we want to promote that in patients. I think just trying to focus on positives could be transferred to more clinical settings, especially in a potentially negative environment. We're not forcing it as well, of course, there are many questions in which the patient can take in any direction, they're not restricted. (P6) | P1;P6 |
|  | Knowing about it |  | Quote  Before this placement I had never heard of it before, so it helped with the understanding of the tool. (P1)  don't think we've been trained that much if that makes sense… Well, I think I feel almost like middle ground, almost quite neutral about it… In that I don't feel we received an extensive amount of training (P3) | P1;P3 |
| The training for students | Introductory lectures | Pre-meah course lectures | Training videos had value (P1;P2;P4) and could be explore at the students own pace (P4)  Got enough training (P4), although a deeper understanding of the questions would be valuable (P6)  Quotes  I think the fact that we had the lectures before we even started the placement was good because then we could look through and gain the knowledge of what the MEAH tool is (P1)  I think the fact that before the first week of placement, we were given introductory lectures which allowed me to understand what the MEAH was a bit more and why we are doing the study. Then, we I went into the training, I found the information that I was told made more sense to me, rather than being a completely new concept (P2)  I found the training good overall. I liked the recorded lectures as I could work through them at my own pace and really take the time to understand the content. I feel that the training prepared me well for taking part in the placement (P4)  I think the impact the difficulty has on a person’s daily life could be explored further (P4)  I think with the aim of the task, I think we got enough trading, I suppose. (P5)  I felt a little bit clueless going into it. I had a read of the questions being asked prior to going into the interviews however, often people don't understand exactly what you mean by the questions, and I think [myself] having a better understanding what the questions really trying to get to, if I had better understanding [could have helped]. If I could potentially reword it differently, or say, better, if there is a better, if there is a worse, I did rephrase it so, and I think just having a deeper understanding of what the questions really mean would have just helped me in explaining what we were trying to get to. (P6)  I felt a bit clueless, but I wasn't completely as went through the questions the previous day and we tweaked a few of them but. I feel almost like in the middle of ground almost quite neutral about it. I don't feel we received an extensive amount of training. So that I guess is something that I identify that there weren’t any, but I feel in a middle ground.  (P6) | P1;P2;P4;P5;P6 |
|  |  | Value of training within the physiotherapy course | Could help more globally with topics like hope and goals (P1) or more around holistic topics (P2) and give a wider appreciation for stroke or the condition (P3;P4) good for students (P6) and allows good application of what research is like before the dissertation (P4), not yet as it needs to be more refined, it could be applied in a certain way (P5)  Example quote  *Interviewer: Do you think the intervention could be integrated into a university course? Can you explain your answer?*  *P2: Yeah, I think it should be considered for a lot of different health conditions, it can really give meaning behind goals and experiences, and I think that’s really important for patients*  Quotes  I think learning about the MEAH tool in a lecture could help us gain the skills to word questions and communicate with patients in a way that we can direct it towards things like hope and goals. (P1)  Interviewer: Do you think the intervention should be used for student physiotherapists more widely? “Yeah, I think so, I think it’s important that students consider a holistic outlook in terms of treatments and patient care. (P2) I also think that the smaller group sizes helped during the training, as I felt a lot more confident and comfortable to ask things that I wasn’t sure about. (P2)  I think considered it to start with, obviously at the start the foundation of physio are most important such as anatomy but understanding the intervention and effects of it are important when considering patient goals. So maybe it should be used the end of first year, I guess before we start placement (P2)  Interviewer: Do you think the intervention could be integrated into a university course? Can you explain your answer?  P2: Yeah, I think it should be considered for a lot of different health conditions, it can really give meaning behind goals and experiences, and I think that’s really important for patients (P2)  Um, yeah, I guess I'm thinking about the long term. These sorts of conditions like, so when I started off saying about patients in the more chronic stage, but it can get you thinking a bit more about that long-term living with these conditions and if that's managing expectations and it just gets a student thinking a bit more. Um, which is only gonna be a positive thing. Um, I think, yeah, I think it could be really useful for that aspect, really. Just get a wider appreciation for stroke or for whatever condition, in this case stroke. (P3)  I think yeah it should be. I think that patient interaction is extremely important… I can imagine often gets missed out upon I know. (P3)  “I think that in an ideal world all physios would get this placement at some point because I think it offers a unique opportunity and is really beneficial especially before completing a dissertation (P4)  I don't think yet. It's just not I don't think it's refined enough. I think it's, it's an interesting way of, of getting information from your patient. I just don't know how you would apply it quite yet to the recovery. Or if it's just like I think we've mentioned as well, on Monday or Tuesday, where it's like, maybe you just need someone to talk to. And that's kind of the way you trigger using that kind of intervention. And you put that into your notes like, say no physical rehab today, but applied math like intervention. And I don't know, we'll see we've kind of put an objective description of it, maybe something along those lines. (P5)  With patients in a more chronic stage, it can get you thinking a bit more about that long-term living with these conditions. And if that's managing, expectations, it just gets a student thinking a bit more, which, again, is a positive thing. I think it could be useful for that aspect, really, and just have a wider appreciation for stroke, or for whichever condition.  (P6)  I think the course should be research and evidence-based teaching, so as this is research project I can't really see any negative of that really having a wider understanding or appreciation of different ways of approaching situations. I think these sorts of things can get the students, especially the brand-new undergrads, thinking about or gaining an appreciation for what it's like for someone else. (P6)  I don’t see why not; I think again to keep therapists thinking and keeping their appreciation for someone else's perspective. It's not solely restricted to stroke or neurological conditions. Someone could have, peri-trauma, or whatever it might life changing physically and mentally. Focusing on the sort of questions we went through on the MEAH interview, like feelings of hope and talking about and being aware of the emotions. Again, it's just useful for whatever department, whatever area of work you're in, if that's even physio, if that's, you know, another department like medicine, I could see its application. It's another conversation, isn't it? So I think always positive for patients. (P6) | P1;P2;P3;P5;P6 |
|  | Simulation needs | Watching videos | Quotes  Watching the YouTube videos of the recorded examples of the students carrying out the previous version of the MEAH gave me an idea of what to expect. (P1)  I liked the recorded lectures as I could work through them at my own pace and really take the time to understand the content. I feel that the training prepared me well for taking part in the placement (P4) | P1;P4 |
|  |  | Practice | Practice is needed (P1; P2; P3;P6), training was enough but with practice you learn (P5).  Example quote  *After I had completed my interview, I was doubting whether I had asked the questions in the right order or with the right tone for example. This was probably just because it was the first time trying out the MEAH with participants. It’s not until you perform something that you think… did I do this wrong? So maybe just having a practice before*. (P2)  *I think we got enough training, I suppose. And it's just really trial and error, it is a numbers thing. So, you kind of get a bit better from it each time*. (P5)  Quote  It might have been helpful for us to actually practice carrying out the MEAH on each other first before going out to the stroke patients. Then we could get a feel of the structure and flow of the tool with some role play from other students (P1)  think maybe, having a practice of the interview questions before on other students. After I had completed my interview, I was doubting whether I had asked the questions in the right order or with the right tone for example. This was probably just because it was the first time trying out the MEAH with participants. It’s not until you perform something that you think… did I do this wrong? So maybe just having a practice before. (P2)  so I felt a little bit clueless going into it and I had a read through the questions before. But often some people don't understand exactly what you mean, and those sorts of things and I think just having a better understanding of the questions really trying to get to if I better understand you that I could have you know which I did reword a few times to help them understand more of what I was trying to get to…. could potentially reword differently or say it better. I don't know how I rephrased it, but you know, I did rephrase it. I think it's having a deep understanding of what questions, what the questions are really, what they, what they really mean, would have just helped me in explaining what we're trying to get to, really.   (P3)  I think it may have been beneficial to have practiced asking the questions in the intervention to each other so that I was more familiar with the questions. I think this would have increased my confidence when conducting my first interview with a patient (P4)  I think with the aim of the task, I think we got enough training, I suppose. And it's just really trial and error, it is a numbers thing. So, you kind of get a bit better from it each time.  . (P5)  I felt a little bit clueless going into it. I had a read of the questions being asked prior to going into the interviews however, often people don't understand exactly what you mean by the questions, and I think [myself] having a better understanding what the questions really trying to get to, if I had better understanding [could have helped]. If I could potentially reword it differently, or say, better, if there is a better, if there is a worse, I did rephrase it so, and I think just having a deeper understanding of what the questions really mean would have just helped me in explaining what we were trying to get to. (P6) | P1;P2;P3;P5;P6 |
|  |  | Understanding how to apply questions further or deeper understanding of the questions | Quote  Also, I think we have a lot of freedom on this placement, which is a good thing, but I think relating it back to the main questions is something we could work on. Finding ways to use the freedom of questioning to gain more information, but not deviate too much. I feel unsure if I am asking the right follow up questions (P1)  I think he's having a bit more time to chat about the questions and just with you know with the with our lead or with other students and just you know have a bit more of a chat about it. Just speaking, not especially that we're all on the same page with questions, just so we all understand you know our perspective of what questions we’re asking as everyone’s perspective may be different of what a question is asking. Everyone could interpret that differently from me and I think yeah, just having a bit more time to sit down with everyone, having a bit of time to chat about everything. Would've been a small change.  (P3)  I think, having a bit more time to chat about the questions, with the research lead and other students, so we can all not so much all be on the same page, with what the questions are, however just so we can all understand that our perspectives of what the question is asking may be different, especially open-ended questions that we're trying to promote. Everyone would interpret that a little bit differently, and I think just having a bit more time sit down with everyone's having a bit more time to chat about it, I think would have been something I'll change.  (P6) |  |
|  |  |  |  |  |

The different versions of the MEAH

The initial piloted MEAH tool version 3.7a used in the pilot version

|  |  |  |
| --- | --- | --- |
| **Patient info** | Name |  |
|  | Gender / Age |  |
|  | Social history |  |
|  | 1st stroke info / 2nd stroke info |  |
|  | How long (mth/yr) have you participated in the community centre activity? |  |
|  | Email |  |

|  |  |  |
| --- | --- | --- |
| **Area** | **Question** | **Answer** |
| Q1:  Difficulty **In general** | Which aspect / area of life you are finding difficulty to adapt to after stroke? |  |
| Q1 – extension:  Difficulty  **Role and identity** | Are there any change to your role and identity that you may not fulfil after stroke? |  |
| Q1 – extension:  Difficulty  **Participation of activity** | Are there any restriction to your participation of activity on individual level or social level? |  |
| Q1 – extension:  Difficulty  **Everyday functions** | How did stroke change your everyday life functions? |  |
| Q2:  MEAH  **Hope** | Hope - How hopeful are you right now you can change this difficult condition? | High (i.e.hopeful) / Middle (i.e. accept it could not change) / Low (i.e. no hope) |
| Q3:  MEAH  **Acceptance** | Acceptance - To what extent are you currently able to accept this difficult condition? | High (i.e. embrace) / Middle (i.e. acknowledge) / Low (i.e. not accept) |
| Q4:  MEAH  **Energy** | Energy - How much energy do you have to deal with this currently? | High / Middle / Low |
| Q5:  MEAH  **Feelings** | Feeling - How do you feel about it ranging from positive/pleasant to negative/unpleasant? | High (i.e. pleasant) / Middle / Low (i.e. unpleasant) |
| Q6:  Change of hope over the course | Over the course of your recovery journey, do you experience any change in hope? |  |
| Q7a:  Factors that could impact hope  **Personal goal** | Do you have any personal goal now?  If yes, do you think the goal has / will give any impact on your hope?  Do you think you can use this difficulty as your goal?  Have you ever thought about living your life again with less restriction from this difficulty? Why? |  |
| Q7b:  Factors that could impact hope  **Physiotherapy support** | Do you receive physiotherapy now?  If yes, does physiotherapy give you any impact on hope?  If no, do you think exercise can help your condition? |  |
| Q7c:  Factors that could impact hope  **Caring network** | Who is your closest caring network? Are they paid or non-paid carer?  Do they give you any impact on hope?  i) In terms of presence, ii) wording of encouragement / discouragement, iii) suggestion on how to change the difficulty? |  |
| Q7d:  Factors that could impact hope  **Other people with stroke experience** | In the past, do you know anyway close with you who has stroke?  In community center here, what do you observe and what do you get from being here?  Do these community stroke members give you any impact on hope / stress / comfort?  Do you want to continue to join and enjoy the social environment? |  |
| Q7e:  Other factors that could impact hope | Do you have any other factors that could give you an impact on hope?  i) faith in yourself, ii) spiritual belief, iii) others? |  |

**Version 3.8 Therapeutic MEAH Tool (to aid in-person interactions)**

* Purpose of conversation today is to talk about a difficulty you are facing right now. Are you happy to talk about that?

**Question to understand challenge or suffering:**

**What is the one aspect of your life right now that you are finding most difficult to adapt to?**

**Alternatives:** Answer: No difficulties OR says fine? Question: **Ask about change OR disruption to your roles and identity, meaningful activities or relationships**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **AREA** | **Question** | **Scale** | | |
|  |  | **Extreme high or complete response** | **Middle or average response** | **Extreme Low, no ability or response which shows rejection** |
| Q2:Hope | How hopeful are you right now you can change this? | Completely hopeful  😀 | Accept it may not be possible to change  😐 | See no hope or ability to change  ☹️ |
| Q3:Acceptance | To what extent are you able to accept this difficulty currently? | Completely able to embrace  😀 | Can acknowledge it  😐 | Not able to accept and reject it  ☹️ |
| Q4: Energy | How much energy do you have to deal with this currently? | Very high energy  😀 | Average energy  😐 | No energy  ☹️ |
| Q5: Feelings | How do you feel about it ranging from positive/pleasant to negative/unpleasant? | Extremely pleasant and positive feelings  😀 | Average or normal feelings towards it  😐 | Extremely unpleasant and negative feelings  ☹️ |

1. ***Exploring the difficulty further.***

|  |  |  |
| --- | --- | --- |
| **Area** | **Question** | **Note** |
| Difficulty extension  **Change** | Does the way you think about the difficulty change over time? |  |
| Difficulty extension  **Role and identity** | Does the difficulty impact on any important roles (parent/someone who works) and/or identities/groups (sports group, community group) that you associate(d) with? |  |
| Difficulty extension  **Social Participation of activity** | Does the difficulty influence, change or impact meaningful relationships you with others who are close to you? |  |
| Difficulty extension:  Difficulty  **Everyday functions** | Does the difficulty influence, change or impact tasks or accomplishments you would like to make? |  |

*Note: Focus here is about the present challenge and recent change but it is ok to extend this for context and may well be that immediately after stroke is considered*.

1. ***How to help the difficulty***

|  |  |  |
| --- | --- | --- |
| **Area** | **Question** | **Note** |
| Factors that change hope  **Activities to help the difficult** | Are you aware of activities that may help? *Prompt: This could include both individually or as a group for people with stroke but also activities that you enjoy within the community.*  Have you experienced any of these activities? *Prompt: is there a reason for not considering this*  Is there things you can do to aid access? Or are their barriers that prevent you gaining access? |  |
| Factors that could change hope  **Cognitive strategy** | Is there any personal characteristics or attribute that have helped you previously? that you have help you keep going (i.e., determination, persistency)? |  |
| Factors that change hope  **Cognitive strategy** | Is there a different way to look on the difficulty or situation?  Are others with different views to a similar or the same experience useful?  Prompt is shared knowledge useful? |  |
| Factors that could change hope  **Inspiration from others experience** | Do you know anyone close to you (e.g., partner, friend) that can help?  Are there others you admire that could offer you ideas of how to manage the difficulty? |  |

1. ***Identify a goals for the difficulty***

|  |  |  |
| --- | --- | --- |
| **Area** | **Question** | **Note** |
| Identifying goals  **Personal goals** | Is there a goal or goals we could consider that would help the difficulty?  What timeline would you like to see for this?  Consider SMART principles |  |
|  | Can we consider what you would do to meet that goal? *Prompts: what routes, pathways are there to this, what support is needed or external help or information provision could be given.* |  |

**Version 3.9 Therapeutic MEAH Tool (to aid in-person interactions)**

**Q1: Purpose of conversation today is to talk about a difficulty you are facing right now. Are you happy to talk about that?**

**Q2: What is the one aspect of your life right now that you are finding most difficult to adapt to?**

**Alternatives:** Answer: No difficulties OR says fine? Question: **Ask about change OR disruption to your roles and identity, meaningful activities or relationships**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **AREA** | **Question** | **Scale** | | |
|  |  | **Extreme high or complete response** | **Middle or average response** | **Extreme Low, no ability or response which shows rejection** |
| Q2:Hope | How hopeful are you right now you can change this? | Completely hopeful  😀 | Accept it may not be possible to change  😐 | See no hope or ability to change  ☹️ |
| Q3:Acceptance | To what extent are you able to accept this difficulty currently? | Completely able to embrace  😀 | Can acknowledge it  😐 | Not able to accept and reject it  ☹️ |
| Q4: Energy | How much energy do you have to deal with this currently? | Very high energy  😀 | Average energy  😐 | No energy  ☹️ |
| Q5: Feelings | How do you feel about it ranging from positive/pleasant to negative/unpleasant? | Extremely pleasant and positive feelings  😀 | Average or normal feelings towards it  😐 | Extremely unpleasant and negative feelings  ☹️ |

1. ***Exploring the difficulty further. (first two questions could be used with the above for a short version or as a screening tool)***

|  |  |  |
| --- | --- | --- |
| **Area** | **Question** | **Note** |
| Impact | Has the difficulty has impacted you psychologically? If so can you explain |  |
| Suffering | Has the difficulty caused suffering for you or people who are close to you? If so can you explain |  |
| Difficulty extension  **Change** | Does the way you think about the difficulty change over time? |  |
| Difficulty extension  **Role and identity** | Does the difficulty impact on any important roles (parent/someone who works) and/or identities/groups (sports group, community group) that you associate(d) with? |  |
| Difficulty extension  **Social Participation of activity** | Does the difficulty influence, change or impact meaningful relationships you with others who are close to you? |  |
| Difficulty extension:  Difficulty  **Everyday functions** | Does the difficulty influence, change or impact tasks or accomplishments you would like to make? |  |

*Note: Focus here is about the present challenge and recent change but it is ok to extend this for context and may well be that immediately after stroke is considered*.

1. ***How to help the difficulty***

|  |  |  |
| --- | --- | --- |
| **Area** | **Question** | **Note** |
| Factors that change hope  **Activities to help the difficult** | Are you aware of activities that may help? *Prompt: This could include both individually or as a group for people with stroke but also activities that you enjoy within the community.*  Have you experienced any of these activities? *Prompt: is there a reason for not considering this*  Is there things you can do to aid access? Or are their barriers that prevent you gaining access? |  |
| Factors that could change hope  **Cognitive strategy** | Is there any personal characteristics or attribute that have helped you previously? that you have help you keep going (i.e., determination, persistency)? |  |
| Factors that change hope  **Cognitive strategy** | Is there a different way to look on the difficulty or situation?  Are others with different views to a similar or the same experience useful?  Prompt is shared knowledge useful? |  |
| Factors that could change hope  **Inspiration from others experience** | Do you know anyone close to you (e.g., partner, friend) that can help?  Are there others you admire that could offer you ideas of how to manage the difficulty? |  |

1. ***Identify a goals for the difficulty***

|  |  |  |
| --- | --- | --- |
| **Area** | **Question** | **Note** |
| Identifying goals  **Personal goals** | Is there a goal or goals we could consider that would help the difficulty?  What timeline would you like to see for this?  Consider SMART principles |  |
|  | Can we consider what you would do to meet that goal? *Prompts: what routes, pathways are there to this, what support is needed or external help or information provision could be given.* |  |
|  | Do you feel confident that you could undertake these activities to meet your goal? |  |