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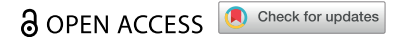


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RESEARCH PAPER



A qualitative study exploring how stroke survivors' expectations and understanding of stroke Early Supported Discharge shaped their experience and engagement with the service

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ABSTRACT

Purpose: To explore how stroke survivors' expectations and understanding of Early Supported Discharge (ESD) helped them make sense of their experiences, and shaped their engagement with the service.

Methods: Data were collected as part of a study of large-scale implementation of stroke ESD: the WISE realist mixed-methods study. Semi-structured interviews were conducted with five purposefully selected stroke survivors from six sites in England implementing stroke ESD ($n = 30$). Participants were aged 32–88 years (20 males). Interviews were audio recorded, transcribed verbatim and transcripts were analysed using reflexive thematic analysis.

Results: Three overarching themes were identified: (1) ESD as a post-stroke recovery tool, (2) desire to recover quickly, (3) psychosocial impact and support. Stroke survivors were uncertain about what to expect when they first entered the service, however, their experience of ESD exceeded their expectations and increased their engagement with the service. Stroke survivors especially valued the goal-oriented approach the team adopted. Rehabilitation at home was perceived as positive and practical, encouraging independence within real-life contexts. Psycho-social support played an important role in the stroke survivors' rehabilitation.

Conclusions: Ensuring stroke survivors are fully informed about ESD and what to expect, optimises engagement with the services, improves experience and could enhance outcomes.

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► IMPLICATIONS FOR REHABILITATION

- Informing stroke survivors about what to expect from ESD services could optimise engagement and improve their experience.
- The provision of personalised and target focussed therapy at home improves stroke survivors' experience and could potentially accelerate recovery.
- Preparing stroke survivors early for discharge from ESD can reduce anxiety and enhance engagement with the service.


Introduction/background

Early supported discharge (ESD) is an intervention recommended as part of the National stroke service model in England [1,2]. The intervention is designed to facilitate transfer of care from hospital to home as soon as stroke survivors are medically stable [3]. Stroke survivors should receive the same therapy at home from a stroke specialist multi-disciplinary team (MDT) as they would have received if they had remained in hospital [4,5]. This potentially involves therapists such as physiotherapists, occupational therapists and speech and language therapists visiting the home for up to 45 min per day, 7 days a week for up to 6 weeks depending on the stroke survivor's assessed needs and goals.

Findings from clinical trials suggest that for stroke survivors with mild to moderate stroke-related disabilities, ESD can enhance independence and satisfaction, while reducing mortality and

future institutionalisation [6,7]. In addition, it has been suggested that the home environment can facilitate stroke survivors to self-manage their post-stroke recovery through recognition of their capability and accessing of personal resources [8,9]. Rehabilitation for stroke survivors has become a national priority [10], whereby national policy in the United Kingdom (UK) is driving towards community-based care and promoting/prioritising closer integration of hospital and community sectors [11]. Despite national policy and the significant evidence suggesting the benefits of ESD, there are still some regions where ESD service provision varies or is not available at all [12,13].

Stroke remains one of the major causes of mortality and morbidity globally, with over 12.2 million strokes each year affecting one in four people over the age of 25 years during their life time. There are over 101 million people currently living with stroke across the world [14]. This equates to over 100,000 new stroke

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each year in the UK and 1.2 million stroke survivors in the UK [15]. It is responsible for a wider range of disabilities than any other condition [16], and up to two thirds of stroke survivors discharged from hospital have a disability, requiring support with activities of daily living [17,18]. In addition, the incidence and prevalence rates are predicted to grow 34% by 2035[19], increasing the socio-economic burden on the individuals, carers and the nation [3,20]. Financial costs of stroke to health and care in the UK alone is anticipated to rise from £26bn to between £61bn and £91bn [4]. The need to optimise outcomes and independence for stroke survivors is therefore paramount.

Stroke survivors face inevitable changes and challenges following discharge from hospital [21], especially as they adjust to their new routines, determine their expectations for recovery [22,23] and re-establish their independence [24]. Although much quantitative research about the effectiveness of ESD is available, the exploration of stroke survivors' experiences is relatively scarce. Yet, the importance of context pertaining to successful evidence-based practice, such as the patients' subjective perceptions, interpretations, and evaluations are increasingly recognised [25]. With evidence suggesting that patient's expectations can contribute to the effectiveness of therapeutic interventions [26], the exploration of patient's expectations of ESD and how these relate to their experiences of the service models is warranted.

ESD as an intervention, plays an important part in the stroke care pathway; supporting rehabilitation and prioritising recovery following stroke. This study aims to gain insight into the stroke survivors' understanding of ESD, and the consequent experience of the service they received.

Methodology

Study design

The study comprised analysis of stroke survivors' interview data collected as part of the larger mixed method study – Large-scale implementation of stroke early supported discharge: the WISE realist mixed-methods study [12,27]. WISE investigated mechanisms and outcomes of implementing ESD at scale in real-world situations, to establish which models of ESD are most effective and in which contexts. Stroke survivor data were collected utilising semi-structured interviews.

Sample

Five stroke survivors from each of the six ESD services ($n = 30$ stroke survivors) in England were purposively selected as part of the WISE study [27]. Services involved in this study were located in both rural and urban sites and ESD was provided by community based multidisciplinary teams. Stroke survivor eligibility criteria can be seen in Table 1.

Procedure

Potential participants were identified and approached by an ESD clinician, during a routine home visit. The clinician introduced the study to the stroke survivors and provided a study information sheet. Interested participants were asked for permission to share their contact details with the research team. Potential participants were then contacted by phone by the 3rd author (AB) who was to conduct all the interviews. AB (a Research Fellow on the original WISE team with significant experience in stroke rehabilitation research and conducting interviews and focus groups) introduced himself, explained the study in more detail, and arranged the

Table 1. Eligibility criteria.

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> Stroke survivors admitted to ESD services and Having sustained first or recurrent stroke Medically stable Able to give informed consent Aged 16–100 years In the services' caseload at the time of recruitment. 	<ul style="list-style-type: none"> Stroke survivors not eligible for ESD Stroke survivors without adequate understanding of the English language to participate in the interviews.

interview at a time and place convenient for the participant. Written informed consent was obtained at the beginning of the interview.

A semi-structured interview schedule was developed to guide the discussions facilitating generation of rich qualitative data [28]. The interview guide covered broad areas such as the stroke survivors' experience of leaving hospital to return home, the ESD service, perceived outcomes of the service, and suggestions for improvement.

Interview audio-recordings were transcribed verbatim and redacted by the original research team, prior to sharing the data for the purpose of the present study to maintain participant anonymity.

The original WISE study received ethical approval from the East Midlands - Nottingham 1 Research Ethics Committee Ref: 18/EM/0160 on 23 July 2018, during which the data were collected from participants by semi-structured interview. The present study received approval from the University of Nottingham Division of Rehabilitation, Ageing and Wellbeing Ethics Committee on 4 May 2020 to analyse the data from the transcripts which were redacted and anonymised by the original study team.

Analysis

The interview transcripts were analysed using pen and paper by both author 1 (TC) and author 2 (KK). Analysis was undertaken iteratively, using reflexive type of thematic analysis [29,30]. Whilst this methodology was flexible, it required prolonged data immersion and reflection to identify themes from the participants' narratives [31,32]. The data were approached inductively at the semantic level, whilst continuously monitoring and managing any potential bias. KK led the analysis by actively engaging with the data [33] proceeding through stages of data familiarisation, where initial notes were taken, followed by coding from text of analytic interest [34]. The coding process involved constant comparison of data similarities and questioning the assumptions the researcher was making about the data as described by Braun, Clarke [30] in a process of asking oneself a series reflexive questions during the analytical process. TC also familiarised themselves with the data by reading and re-reading the transcripts and making manual notes of what they considered to be important issues for exploration. Ultimately, themes were constructed by KK, and presented to TC. Both researchers discussed the presented themes and made adjustments based on individual notes, understanding and interpretation of the data. Transcripts were revisited where necessary and further iterations of the identified themes were discussed to refine them and gain consensus [35]. There were no outstanding issues that could not be resolved. At this stage both TC and KK agreed that inductive thematic saturation had been achieved as no new themes related to the study objectives could be identified in the data [36]

Results

Stroke survivor interviews were completed between November 2018–November 2019. Thirty face-to-face interviews lasting

between 24 and 70 min (mean 45 min) were conducted in the participants' homes by AB. Some participants requested that a spouse or partner be present at the interview otherwise interviews were conducted on a one to one basis. One participant withdrew from the study at the point of signing the consent form. The reason given was that they had changed their mind.

Participants

Table 2 provides basic participant characteristics. Barthel scores [37] are presented to indicate the severity of stroke of the participants at admission to the ESD service. The score measures stroke survivor's functional ability in relation to activities of daily living and mobility and provides a score from 0 to 20 with a score of 0 indicating total dependence and 20 being totally independent.

Findings

The interviews yielded rich data about participants' experiences related to the ESD service in terms of their post-stroke recovery.

Table 2. Participant demographics.

	Site A	Site B	Site C	Site D	Site E	Site F	Combined data all sites
Sex							
Male	3	3	2	4	4	4	20
Female	2	2	3	1	1	1	10
Age Range	53–86	53–78	47–86	32–74	38–79	57–88	32–88
Barthel range on admission	15–20	11–19	13–20	14–20	10–19	8–18	13–20
to ESD (out of 20)	(mean 18.2)	(mean 14)	(mean 16.4)	(mean 17.8)	(mean 14.2)	(mean 13.6)	(mean 15.7)
Length of stay on ESD Team	15–45	42–42	9–46	34–107	56–83	36–74	Range 9–107 Mean 46.6

Table 3. Overarching themes and subthemes.

Theme	Subtheme	Description	Example quote
ESD as a post-stroke recovery tool	Uncertainty	Being informed about a referral for further support at home, uncertain about what it entails and what will happen after it is finished.	"We didn't really get any information on it to be honest with you" (B5- BI 13↓ LOS 42↓)
	It serves its purpose	Continuous support following discharge from hospital is helpful when trying to navigate the new routine.	"I feel it's.. it's done what it set out to do" (A1- BI 20↑ LOS 42↓)
	Rehabilitation dose	The required intensity and frequency of rehabilitation is an individual matter. What is too much or enough for one, might not be enough for the other.	"The only benefit I suppose really if I could get more therapy might.. that I might come right quicker" (F1- BI 8↓ LOS 49↑)
Desire to recover quickly	Trust in health care professionals' knowledge and expertise	The perception that nothing wrong should be pointed out, because "they" know what they are doing and why.	"But no I think they're.. they know.. they know their job don't they? Very professional. They know their job" (C2- BI 13↓ LOS 27↓)
	Goal oriented rehabilitation and support	A focus on the stroke survivors' rehabilitation goals and needs, and appropriate signposting is highly valued.	"It fulfils your potential. Because you don't know what your potential is at this point in time. When you come out of hospital you've achieved so many things, but you still.. you have to take the step forward to be a little bit independent" (B3- BI 11↓ LOS 42↓).
	Pro-recovery headspace and taking control	The ability to monitor one's progress, reinforce self-determination, and active participation in the rehabilitation, makes the recovery process/ progress more reassuring.	"That she.. that has really helped with that sense of purpose with.. is.. is to give some.. give that validity to the very small tasks" (A1- BI 20↑ LOS 42↓)
Psychosocial impacts and support	Home is a logistical rehabilitation environment	The home environment provides a familiar environment for stroke survivors to regain their independence, while returning to their usual routine and roles.	"I've liked it more at home obviously.. because it.. it's.. it's.. it's helped with my own sense of independence and autonomy" (A1- BI 20↑ LOS 42↓)
	The loss of "oneself" (identity)	The emotional and socioeconomic impact of trying to adjust around one's "new" abilities, while anticipating recovery can get overwhelming.	"If I fall, I bloody fall. ..The end of the world for me when I'm lying on the floor, not being able to get up" (E1- BI 14↓ LOS 56↑).
	Support network and professional assistance	Having a significant other(s) involved in the rehabilitation process is equally as important as the emotional support by the specialist team. This allows the recovery process to be more manageable.	"Because the mental aspect plays into so many other things in terms of your recovery, like motivation and things like that" (B1- BI 14↓ LOS 42↓).

Three overarching themes and respective subthemes were developed (Table 3). Participant's quotes are identified by the site coded A–F, followed by a number indicating the order of interview at that site highlighted in bold. The Barthel index score [37] for each participant's quote is presented as BI with an arrow indicating whether they are above or below the mean for all study participants. Similarly the length of stay is presented as LOS with the arrow indicating whether it was above or below the mean.

Themes are identified from the stroke survivors' expectations, perceptions, understanding and experiences of the ESD services, providing deeper insight into what they valued about the service and what they thought could be improved.

ESD as a post-stroke recovery tool

Uncertainty

Uncertainty related to the start of the service, what to expect and what it entailed, as well as what would happen when the ESD service was withdrawn. For the majority of participants the first time

they were informed about ESD was at the hospital, either before or during their discharge, usually by the resident physiotherapist.

I was in hospital when it was mentioned that this Discharge team would come in and see me at home. (B3- BI 11|LOS 42|)

However, half of the participants articulated that they were uncertain of what the services were and had only a brief idea of what it might involve. Consequently, at the time of the interview, few were unsure of what “ESD” really referred to even though they were under the care of the ESD team.

I don't think I have heard of Early Support Discharge, except when you [the interviewer] made me the phone call. (F1- BI 8|LOS 49|)

Thus, they did not appear to have a clear idea of what support they had been receiving from the ESD service as opposed to other services such as reablement teams or other paid carers.

So what part of the treatment that we have received so far comes under ES. the early thing? Is it the support like dressing and washing or is it the. occupational therapist? Or the voice. (C2- BI 13|LOS 27|)

These participants' perceptions seemed to be associated with the method by which the ESD service was introduced to them. For example, the hospital staff not using the appropriate term “Early Supported Discharge” when informing the stroke survivors about their further rehabilitation within the community appeared to have an impact on the stroke survivors' understanding of the care they received.

A few days. a day or so in when I started to. when I met the. the physiotherapist in hospital. And you know started to help walk and trying to navigate with my. my. my vision. with my vision. how to get around. She ...didn't call it Early Discharge or anything. (A1- BI 20|LOS 42|)

The lack of previous knowledge about what the service was set out to do, led to stroke survivors to having low expectations, or leaning towards the assumption that it would simply involve more physiotherapy. Subsequently, when asked about their first expectations, many of them felt that the actual experience exceeded any initial hopes.

No. I didn't know anything about it at all. So I was amazed and pleased that it did, especially. I had as I said such a lot of problems . people really putting and helping me out. I was astounded at that. So I'm delighted with it. (E2- BI 12|LOS 57|)

Furthermore, many participants expressed concern and uncertainty about what would follow their discharge from ESD. This was often related to them hoping not to miss out on the opportunity of getting better and the worry of not having access to the appropriate support.

I don't know. I. I was just worried after this six weeks. What happens after this six weeks. Because you know you have these people come four times a week and then all of a sudden. what's going to happen? And they said there is another plan [inaudible]. but it could take time. (C5- BI 17|LOS 37|)

It serves its purpose

Regardless of the participants' uncertainty, all the respondents conveyed positive views of the service. They thought it was useful to have a continuous and prompt support available upon discharge from hospital.

It's. it's a good service because when you come out,. otherwise you'll be straight to the doctor probably. So it is a good. good idea. (A3- BI 20|LOS 45|)

Participants reported that they felt immediately supported by the team, and that they were given the needed time and attention in order to recover quicker.

The main benefit I think is the fact that it's immediate. There's not this gap between hospital and coming out. (C1- BI 19|LOS 9|)

They therefore felt that the service played a crucial role in their route to recovery. Many participants expressed that they had started to notice improvement and had regained their confidence.

I couldn't even sit up, so physio's have, well, they have made a massive improvement in me really. And I can see that. Yeah. (E3- BI 19|LOS 71|)

In fact, most of the interviewees assigned their progress to the fact that the ESD team motivated them to work towards their recovery goals.

Which is I think as much the point as the benefit. I've enjoyed them being here. I've enjoyed them pushing me, because if they hadn't pushed me I wouldn't have done it. (D4- BI 18|LOS 42|)

Many participants would recommend the service to anyone living with stroke-related difficulties to help them adjust to the new routine better. The service was so highly valued by the stroke survivors that they sympathised with anyone in a similar situation who would need such a service and might not have had access to it.

I think it's a very good service. And I think, you know, they should give it to everybody when they come out from hospital if they need it. You know. Because I did need it. I was at a point, but I wasn't at a very good point when they discharged me from hospital. You know there was a lot more to do. (C3- BI 13|LOS 46|)

The rehabilitation dose

There was some variance of service models delivered across the six sites. While some services offered a seven-day service, others operated five days a week, which affected the amount of weekly sessions stroke survivors received. Hence, satisfaction with the given service appeared to be related to what they were offered.

I'm happy with the five day week because I mean that's how it works. But a seven day obviously would be better. (D4- BI 18|LOS 42|)

The dose of rehabilitation being offered in terms of frequency and intensity generated diverse views between the participants. The majority reported that they received enough sessions of a reasonable frequency with the ESD team. “*I think it's been just the right amount*” (A1- BI 20|LOS 42 |). Some of the participants stated that the amount of home visits they were getting was just enough to manage in terms of time and their energy levels. Even though they wished for more therapy to speed up their recovery, they acknowledged that it could be ultimately counterproductive. “*I think it's probably to a certain degree as much as I could probably take*” (D4- BI 18|LOS 42|). Equally, some also said that they wanted more or longer support. However, they felt a sense of responsibility towards the service providers and fellow stroke survivors, and so they would not want to receive more rehabilitation at the cost of someone else.

I wouldn't want to take it. I wouldn't like to take it away from people who need it more than me if you know what I mean... I think it's enough you know. (D1- BI 18|LOS 107|)

In contrast, some stroke survivors did not mind being discharged from the ESD service, as they felt that they did not need the support and could manage their recovery themselves.

No. Because I've. you know for some people I'm sure it's very good, but I just don't. don't really feel as though I really needed it. (A5- BI 20|LOS 15|)

Trust in health care professionals' knowledge and expertise

Stroke survivors appeared to have a great deal of respect for the ESD team and reported holding them in great authority. Stroke

survivors trusted the professional skills of the ESD team members, and so were willing to do anything they were told to without challenging it.

I'll leave up to the early discharge team of when they think it's best for me, because let's face it, I could say, well I don't want you's anymore. (B2- BI 13↓ LOS 42↓)

Stroke survivors did not want to complain about anything related to ESD as they were thankful for whatever support they could access.

So. is. is that because you're very grateful to be getting the service, that you're just happy to accept whatever they. whatever the visit is, yeah?. (E3- BI 19↑ LOS 71↑)

Desire to recover quickly

Goal oriented rehabilitation and support

For all participants it was paramount to return to their usual roles and routines as soon as possible. Working towards a set of personalised goals was highly valued and increased expectations of further recovery. Most of the participants felt that the time spent with the ESD therapists contributed to their overall recovery outcomes, because the ESD team focussed on their goals and kept reviewing their rehabilitation plan accordingly.

What I found with the ESD team was that they would come. . there was no sort of timetable. they would stay here as long as I needed them, you know what I mean? There was never a case of 'I've got to go'. . I know they've got other patients to look after, but this was a very personal experience for me. And certainly I wouldn't be where I am now as far as improvement if it wasn't for the ESD team. (C1- BI 19↑ LOS 9↓)

Establishing individual rehabilitation goals allowed the team to prepare a set of personalised exercises, which the stroke survivors practiced during and in-between the sessions, offering them a sense of progress. The majority of the participants accepted the prescribed exercise plan as the mediator for recovery and were determined to work on it as part of their rehabilitation routine.

She set a plan in place of things to do to increase mobility and again we started talking task, because that seemed to be one way of trying to get what I needed and what I wanted to be able to do. And then behind her, there is a team of either physios or I think assistant physios who then come out and work through the plan with you. And when things are too easy they make it harder and add things in so. and they brought with them quite a lot of equipment to enable me to do these things. (F5- BI 10 ↓LOS 47↑)

There was also a consensus amongst the responses that equipment the team provided for the stroke survivors promoted comfort, safety, and mobility around the house and outdoors. The underlying benefit of this was that these aids promoted independence and autonomy, boosting daily functioning and participation within the community.

They've given me. stuff for the stairs and everything, haven't they? Like handrails for the bathroom and things like that. Which have helped. (B5- BI 13↓ LOS 42↓)

Many participants found it also very beneficial that the ESD team was able to effectively signpost them to additional support and community agencies. Subsequently, the stroke survivors gained trust in the ESD therapists and felt comfortable asking for their guidance in terms of facilitation of their continuous recovery and logistical support.

And... I do Pilates. And she. we were on about trying to get back to that. And she was going to try and find out whether there was a Pilates class at the hospital for stroke people, so. she was trying to organise that for me. (A3- BI 20↑ LOS 45↓)

Pro-recovery headspace and taking control

All the stroke survivors reported that their independence and participation in activities of daily living, as well as in their leisure activities, had been impacted by the stroke. Therefore, they emphasised that it was very important to them to challenge themselves, in order to improve as quickly as possible.

I mean I'll do what. like I say, I'll do whatever it takes to. to improve. Just because I'm so determined and I. I want to get back on my feet as quickly as I can really. (D3- BI 19↓ LOS 41↓)

Many participants were interested in additional sources of assistance, such as peer support groups, where they could gain access to the necessary reassurance and shared experiences.

There is. there is like a stroke club isn't there?. She [Rehabilitation Assistant] runs one at the centre just up the road here. I would go. Yeah. Just to talk to like other survivors I suppose. (B5- BI 13↓ LOS 42↓)

This came down to the fact that the stroke survivors were determined to carry on and take charge of their rehabilitation, and subsequent recovery.

But it is about your own determination. It's about making use of what's there. It's about making sure you get everything that is available to you. (F5- BI 10 ↓LOS 47↑)

Home is a logistical rehabilitation environment

Many participants were pleased to move from the hospital setting to the comfort of their own homes. "But you're also in your own environment at home". (B3- BI 11↓LOS 42↓)

The participants also agreed that the service they received at home was more tailored to their needs and adapted to their real environment, enabling them to actively participate in the process and recover their independence within an ecologically valid context.

They always thought ahead in that respect, you know. If I wanted. if they knew that I needed to walk from there to the kitchen, they would leave that place clear. You know what I mean? It's almost like thinking out the box. (C1- BI 19↑ LOS 9↓)

Additionally, rehabilitation at home was perceived as more practical and logistically feasible. As most of the participants were unable to drive, they would have found it difficult to commute to hospital whilst managing their energy levels. Equally, the additional costs for travel would not be affordable to many, especially when considering the increased healthcare costs and reduced income.

They said 'oh you'd probably have to go there for physio'. And I thought, God how am I going to get there? You know, I'd have to have a taxi every day. And I thought, God I can't afford that. And then when they said about these coming in, I was like 'oh that's brilliant'. You know, because it's like £6 each way in a taxi. I wouldn't be able to afford that every. four times a week. (C5- BI 17↑ LOS 37↓)

Psychosocial impact and support

The "loss of oneself" (identity)

It was common for the stroke survivors to find it psychologically challenging to make sense of the new reality that affected their routines and overall quality of life.

I have broke down quite a lot. which has shocked me. Since I've had my stroke in the hospital I think. well since coming out, I've cried a couple of times of being home, since I've been home. But I'm. I was really shocked about that side of things and I. well I don't know where it's come from if that makes sense. (C4- BI 20↑ LOS 39↓)

They tended to become more conscious about the degree of their ability and their need for help, which they perceived as an

extra strain on their family and friends. *“It’s, it’s being a burden to my wife, because she’s having to do everything for me”.* (A4- BI 15↓ LOS 43↓)

Support network and professional assistance

Nonetheless, most of the interviewees agreed that having a stable support system of their significant others eased their rehabilitation strain and enabled effective integration of their changed roles and lifestyles. Since family members were involved by the ESD team, they could effectively support the survivor during their exercise practice in-between the sessions and follow their progress accordingly.

They have involved my wife, but yeah. Yeah, they said that she can walk me round the block and my wife’s quite strict. She makes sure I do my exercise. Yeah. (E3- BI 19↑ LOS 71↑)

Equally, the participants felt listened to and emotionally supported by the ESD team. They appreciated that the therapists went over and above their “designated duty”, and apart from accommodating their physical rehabilitation needs they provided the stroke survivors with psychological support, which was essential to boost positive outcomes.

And she has met emotional needs as well as physical. Or done any referrals or any other things that might help get me back in the real world. (F5- BI 10 ↓LOS 47↑)

Nevertheless, some stroke survivors reached out and requested additional psychological assistance and emphasised the importance of it to be part of the routine ESD services being provided, as the psychological recovery might take longer than physical one or may hinder the rehabilitation progress. Moreover, psychological outcomes of post-stroke recovery might become apparent after one’s discharge from ESD.

It’s a good service. Yeah. You need something when you come out of hospital. You need somebody to come and just chat, because, it’s a scary thing. and when they let you out, sort of, yeah, you do need somebody just to chat to really. Because when you say physio, you just think that they’re going to just give you exercises, but she was really helpful. (A3- BI 20↑ LOS 45↓)

Discussion

This qualitative analysis of stroke survivor interview data collected for the larger WISE study [27], explored their expectations, perceptions, and understanding of ESD and how these shaped their experiences and engagement with the service.

The findings suggested that prior to discharge from the acute hospital, stroke survivors did not have enough information about ESD. They did not understand what the service was aiming to provide and therefore were unsure of what to expect of the service. Previous studies have shown that the way in which clinicians are described and introduced to stroke survivors can have a substantial effect on the way in which they are perceived and the way stroke survivors interact with them [38]. Expectations are likely to influence experience [39] and positive expectations have been associated with positive outcomes, patient satisfaction and improvement [40–42]. There is also evidence to show that when expectations of the process of care are different to the service provided, outcomes are poorer and that interventions to prepare patient expectations can be beneficial [40]. This could be particularly relevant in preparing stroke survivors early in the pathway for discharge from the service. Uncertainty has been found to increase patient stress [43]. Providing information has been shown to reduce uncertainty and consequently to reduce stress [43]

including information on expected patient pathways [44,45]. Ensuring stroke survivors are clear about what the ESD service is, what will be provided and what the expectations for them and their families are prior to hospital discharge could potentially manage expectations and optimise outcomes.

The personalised goal setting approach taken by the teams was highly valued by all stroke survivors. Targeting what was most important to stroke survivors and their families motivated, engaged and encouraged them to extend therapy practice outside of formal sessions which has previously been associated with enhancing rehabilitation outcomes [3,46–48]. The participants felt empowered to take control of their recovery, and were able to discuss their rehabilitation goals and needs with the ESD team to facilitate their continuous improvement of rehabilitation outcomes. This, according to Wade [47], forms an essential part of a formula to enhance and optimise rehabilitation.

Coupled with this imperative to hand responsibility and control to the stroke survivors and their family, is the need to focus on the correct environment for rehabilitation to optimise recovery [47]. The provision of rehabilitation at home with appropriate equipment was very much appreciated by all study participants in terms of practicality and ability to target therapy at important functional skills relevant to their home environment. This correlates with previous research showing that rehabilitation practices that are task and context oriented can facilitate the natural progression of functional recovery, through adaptive rehabilitation strategies that compensate for impaired body functions for mild to moderate stroke [49,50]. Outcomes for more severe disability after stroke is less clear [51]. Home based rehabilitation was also regarded as being more accessible in terms of financial costs for families as there were no travel costs for stroke survivors associated with receiving rehabilitation at home. Stroke survivors reported not having to use their limited energy for travel to therapy as being an important aspect of managing fatigue as all energy could be focussed on engaging fully with therapy. Previous studies support the finding that stroke rehabilitation can be more effective when the intervention is delivered in the patient’s home environment [52,53].

Rehabilitation services that are designed to engage and encourage stroke survivors to participate fully and take responsibility for their learning, such as ESD services should optimise recovery potential [54].

The study findings suggest the need for psychological support alongside physical rehabilitation. Stroke survivors’ have to cope with their new circumstances and strong support is crucial for successful management of emotional strain. It is emphasised that psychological care is as important as physical rehabilitation to post-stroke recovery and should be provided in a timely and appropriate manner [55]. The stepped care approach to psychological support following stroke has been recommended in clinical guidelines [1] as have post-stroke psychological care improvement strategies [56,57]. Therefore, routine specialist psychological assessment and assistance might enhance the positive experiences of ESD.

Limitations and future research directions

Interviews were conducted at varying time points between admission and discharge to the ESD service, depending on the participants’ availability, which might have affected their recollections and experiences of the service. The findings emerged from a small sample across specific sites, which should be acknowledged when considering transferability to other populations.

Furthermore, the sample included only one participant with aphasia, which should be also considered when informing evidence-base care provision.

Future research could target specific areas of the stroke survivors' experiences of ESD, such as how their psychosocial factors interact with rehabilitation outcomes reached through ESD and their mental health, whilst addressing previous methodological shortcomings.

Conclusions

When introducing the ESD service to the stroke survivors and their families, acute hospital staff should provide absolute clarity on the structure, process, purpose, and duration of the service before discharge from hospital. This should be reinforced by the ESD team during the admission to the service. It is also essential that stroke survivors understand how ESD differs to other services that they may be offered such as reablement or other care packages. The importance of stroke survivors and carers taking control and fully participating in their own recovery should be highlighted. Finally, managing expectations of stroke survivors and families could improve their experience and satisfaction.

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References

- [1] Intercollegiate stroke working party. National clinical guideline for stroke. 5th ed. 2016. Available from: [https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-\(1\).aspx](https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-(1).aspx).
- [2] National Institute for Health and Clinical Excellence. Stroke rehabilitation: long term rehabilitation after stroke; 2013. Available from: <https://www.nice.org.uk/guidance/cg162>.
- [3] Langhorne P, Bernhardt J, Kwakkel G. Stroke rehabilitation. *Lancet*. 2011;377(9778):1693–1702.
- [4] National Institute for Health and Care Excellence (NICE). NICE impact stroke 2019. Available from: <https://www.nice.org.uk/media/default/about/what-we-do/into-practice/measuring-uptake/nice-impact-stroke.pdf>.
- [5] Mas MA, Inzitari MA. Critical review of early supported discharge for stroke patients: from evidence to implementation into practice. *Int J Stroke*. 2015;10(1):7–12.
- [6] Fearon P, Langhorne P. Services for reducing duration of hospital care for acute stroke patients. *The Cochrane Library*. 2012. Available from <https://pubmed.ncbi.nlm.nih.gov/22972045/>
- [7] Langhorne P, Baylan S, Early Supported Discharge Trialists. Early supported discharge services for people with acute stroke. *Cochrane Database Syst Rev*. 2017;7:CD000443.
- [8] Cobley CS, Fisher RJ, Chouliara N, et al. A qualitative study exploring patients' and carers' experiences of early supported discharge services after stroke. *Clin Rehabil*. 2013; 27(8):750–757. Available from: <http://cre.sagepub.com/content/27/8/750.full.pdf>
- [9] Wottrich AW, Aström K, Löfgren M. On parallel tracks: newly home from hospital—people with stroke describe their expectations. *Disabil Rehabil*. 2012;34(14):1218–1224.
- [10] Stroke Association, James Lind Alliance. Shaping stroke research to rebuild lives. The Stroke Priority Setting Partnership results for investment 2021. Available from: <https://www.jla.nihr.ac.uk/priority-setting-partnerships/Stroke/downloads/Stroke-PSP-results-Full-Report.pdf>.
- [11] NHS England. The NHS long term plan. London: NHS England; 2019.
- [12] Fisher R, Chouliara N, Byrne A, et al. What is the impact of large-scale implementation of stroke early supported discharge? A mixed methods realist evaluation study protocol. *Implementation Sci*. 2019;14(1):1–10.
- [13] Royal College of Physicians. Post-acute Organisational Audit. Generic report. Phase 1: Post-acute stroke service commissioning audit. 2015. Available from: <https://www.strokeaudit.org/Documents/National/PostAcuteOrg/2015-PAOrgGenericReport.aspx>.
- [14] World Stroke Organisation. Global stroke fact sheet 2022; 2022. Available from: https://www.world-stroke.org/assets/downloads/WSO_Global_Stroke_Fact_Sheet.pdf.
- [15] Stroke Association. State of the nation stroke statistics January 2017; 2017. Available from: <https://www.mynewsdesk.com/uk/stroke-association/documents/state-of-the-nation-2017-68765>.
- [16] Adamson J, Beswick A, Ebrahim S. Is stroke the most common cause of disability? *J Stroke Cerebrovasc Dis*. 2004; 13(4):171–177.
- [17] McPherson CJ, Wilson KG, Chyurlia L, et al. The balance of give and take in caregiver-partner relationships: an examination of self-perceived burden, relationship equity, and quality of life from the perspective of care recipients following stroke. *Rehabil Psychol*. 2010;55(2):194–203.
- [18] Nelson MM, Smith MA, Martinson BC, et al. Declining patient functioning and caregiver burden/health: the Minnesota stroke Survey-Quality of life after stroke study. *Gerontologist*. 2008;48(5):573–583.
- [19] Feigin VL, Forouzanfar MH, Krishnamurthi R, et al. Global and regional burden of stroke during 1990–2010: findings from the global burden of disease study 2010. *Lancet*. 2014;383(9913):245–255.

- [20] Feigin VL, Lawes CM, Bennett D, et al. Epidemiology of stroke. In: Harvey R, Macko RF, Stein J, editors. *Stroke recovery and rehabilitation*. New York: demosMEDICAL; 2008.
- [21] Boger EJ, Demain SH, Latter SM. Stroke self-management: a focus group study to identify the factors influencing self-management following stroke. *Int J Nurs Stud*. 2015;52(1):175–187. 2015/01/01/
- [22] Ellis-Hill C, Payne S, Ward C. Using stroke to explore the life thread model: an alternative approach to understanding rehabilitation following an acquired disability. *Disabil Rehabil*. 2008;30(2):150–159.
- [23] Lutz BJ, Young ME, Cox KJ, et al. The crisis of stroke: experiences of patients and their family caregivers. *Top Stroke Rehabil*. 2011;18(6):786–797.
- [24] Kubina L, Dubouloz C, Davis CG, et al. The process of re-engagement in personally valued activities during the two years following stroke. *Disabil Rehabil*. 2013;35(3):236–243.
- [25] Bate PR, Fulop G, Ovretveit N, et al. *Perspectives on context*. London: The Health Foundation; 2014.
- [26] Greenberg R, Constantino M, Bruce N. Are expectations still relevant for psychotherapy process and outcome? *Clin Psychol Rev*. 2006;26(6):657–678.
- [27] Fisher R, Chouliara N, Byrne A, et al. Large scale implementation of stroke early supported discharge: the WISE realist mixed-methods study. *Health Serv Deliv Res*. 2021;9(22):1–150.
- [28] Willig C. *Introducing qualitative research in psychology*. 3rd ed. New York: Open University Press; 2013.
- [29] Braun V, Clark V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3:77–101.
- [30] Braun V, Clarke V, Weate P. Using thematic analysis in sport and exercise. In: Smith B, Sparkes AC, editors. *Routledge handbook of qualitative research in sport and exercise*. London: Routledge; 2016. p. 191–205.
- [31] Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qual Res Sport Exer Health*. 2021;13(2):201–216.
- [32] Clarke V, Braun V. Using thematic analysis in counselling and psychotherapy research: a critical reflection. *Couns Psychother Res*. 2018;18(2):107–110.
- [33] Clarke V, Braun V. Thematic analysis. In: Lyons E, Coyle A, editors. *Analysing qualitative data in psychology*. London: Sage; 2016. p. 84–103.
- [34] Braun V, Clarke V, Rance N. How to use thematic analysis with interview data. In: Vossler A, Moller N, editors. *The counselling and psychotherapy research handbook*. London: Sage; 2014. p. 183–197.
- [35] Braun V, Clarke V. *Successful qualitative research. A practical guide for beginners*. London: Sage; 2014.
- [36] Saunders B, Sim J, Kingstone T, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant*. 2018;52(4):1893–1907.
- [37] Collin C, Wade D, Davies S, et al. The barthel index. *Disabil Rehabil*. 2008;10(2):61–63.
- [38] Greenberg RP, Land JM. Influence of some hypnotist and subject variables on hypnotic susceptibility. *J Consult Clin Psychol*. 1971;37(1):111–115.
- [39] de Lange FP, Heilbron M, Kok P. How do expectations shape perception? *Trends Cogn Sci*. 2018;22(9):764–779.
- [40] Noble LM, Douglas BC, Newman SP. What do patients expect of psychiatric services? A systematic and critical review of empirical studies. *Soc Sci Med*. 2001;52(7):985–998.
- [41] Klaaren KJ, Hodges SD, Wilson TD. The role of affective expectations in subjective experience and decision making. *Social Cognition*. 1994;12(2):77–101.
- [42] Thompson GH, Sunol R. Expectations as determinants of patient satisfaction: concepts, theory and evidence. *Int J Qual Health Care*. 1995;7(2):127–141.
- [43] Madar H, Bar-Tal Y. The experience of uncertainty among patients having peritoneal dialysis. *J Adv Nurs*. 2009;65(8):1664–1669.
- [44] Mishel MH. Uncertainty in illness. *Image*. 1988;20(4):225–232.
- [45] Brashers DE, Hsieh E, Neidig JL, et al. Managing uncertainty about illness: health care providers as credible authorities. In: Dailey RM, Le Poire BA, editors. *Applied interpersonal communication matters: Family, health, & community relations*. New York: Peter Lang Inc.; 2006. p. 219–240.
- [46] Langhorne P, Holmqvist LW. Early supported discharge T. Early supported discharge after stroke. *Acta Derm Venereol*. 2007;39(2):103–108. Mar
- [47] Wade D. Rehabilitation - a new approach. Part two: the underlying theories. *Clin Rehabil*. 2015;29(12):1145–1154. Dec
- [48] Lloyd A, Bannigan K, Sugavanam T, et al. Experiences of stroke survivors, their families and unpaid carers in goal setting within stroke rehabilitation: a systematic review of qualitative evidence. *JBI Database System Rev Implement Rep*. 2018;16(6):1418–1453. Jun
- [49] Veerbeek JM, Wegen E, Peppen R, et al. What is the evidence for physical therapy poststroke? A systematic review and meta-analysis. *PLoS One*. 2014;9(2):e87987.
- [50] Dąbrowski J, Czajka A, Zielińska-Turek J, et al. Brain functional reserve in the context of neuroplasticity after stroke. *Neural Plast*. 2019;2019:9708905.
- [51] McGlinchey MP, James J, McKeivitt C, et al. The effect of rehabilitation interventions on physical function and immobility-related complications in severe stroke: a systematic review. *BMJ Open*. 2020;10(2):e033642. <https://bmjopen.bmj.com/content/bmjopen/10/2/e033642.full.pdf>.
- [52] Govender P, Kalra L. Benefits of occupational therapy in stroke rehabilitation. *Expert Rev Neurother*. 2007;7(8):1013–1019.
- [53] Kwakkel G, van Peppen R, Wagenaar RC, et al. Effects of augmented exercise therapy time after stroke: a meta-analysis. *Stroke*. 2004;35(11):2529–2539.
- [54] Locke EA, Latham GP. Building a practically useful theory of goal setting and task motivation. A 35-year odyssey. *Am Psychol*. 2002;57(9):705–717.
- [55] Stroke Association. Depression and other emotional changes; 2018. Available from: https://www.stroke.org.uk/sites/default/files/user_profile/depression_and_other_emotional_changes.pdf.
- [56] Kneebone, II Stepped psychological care after stroke. *Disabil Rehabil*. 2016;38(18):1836–1843.
- [57] NHS Improvement Stroke. Psychological care after stroke. Improving stroke services for people with cognitive and mood disorders 2011. https://www.nice.org.uk/media/default/sharedlearning/531_strokepsychologicalsupportfinal.pdf.