

# BMJ Open Recovery beyond functional restoration: a systematic review of qualitative studies of the embodied experiences of people who have survived a stroke

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## ABSTRACT

**Objective** To synthesise the qualitative evidence of embodied experiences of people who have survived a stroke, the experiences of making sense of oneself, others and the world in the poststroke bodies.

### Design

Qualitative systematic review.

**Data sources** Five electronic databases, PsycINFO, PubMed, MEDLINE, CINAHL Plus and Cochrane Library, were employed to search for qualitative studies published up to February 2022.

**Inclusion criteria** Literature in English that employed qualitative methods to investigate the embodied experiences of people who have survived a stroke.

**Quality appraisal** Two reviewers independently appraised the quality of the included studies based on the tool developed by Salter *et al* in 2008. It consists of seven questions assessing the credibility and relevance of the studies. Discrepancies were resolved until a consensus was reached.

**Data extraction and synthesis** Thematic synthesis was applied to synthesise the related findings from all the included studies. Two reviewers were involved in the process.

**Results** 1482 records were identified. After the screening process, 34 studies were included in this review. Three analytical themes and their related descriptive themes emerged. Analytical themes included ‘disconnection between oneself, others and the world,’ ‘the transitional period: exploring and negotiating,’ and ‘reconnecting with oneself, others and the world’.

**Conclusion** The findings demonstrated that the embodied experiences of people who have survived a stroke progressed from feeling disconnected to reconnecting with themselves, others and the world. Stroke recovery should not only be limited to functional restoration. Approaching ‘re-embodiment’, the realignment between oneself and one’s body, is crucial in reintegrating with others and the world on the trajectory toward recovery.

**PROSPERO registration number** CRD42020183125

## BACKGROUND

Stroke is one of many cerebrovascular diseases that causes various degrees of impairments and profoundly affects the quality of everyday life of people who have survived a

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This review is the first qualitative systematic review related to the embodied experiences of people who have survived a stroke.
- ⇒ This review advocates the importance of ‘re-embodiment’, the realignment with the poststroke body during the trajectory of recovery.
- ⇒ The literature search was only limited to publications in English; relevant grey literature and studies published in other languages were excluded.
- ⇒ The findings were limited to survivors who had a high willingness to share their experiences and could articulate their experiences through interviews.

stroke. In 2019, 101 million stroke cases were prevalent worldwide.<sup>1</sup> A growing number of community-dwelling people who have survived a stroke is foreseeable due to the ageing societies, the higher stroke survival rates and the more instances of strokes at younger ages who can survive longer.<sup>2,3</sup> Stroke is also one of the leading prevalent causes of disability-adjusted life-years,<sup>1</sup> which indicates that stroke increases mortality and the risk of living with disabilities<sup>1</sup>; moreover, its impact on survivors can be lifelong.

Poststroke disability can be severe and is detrimental to the quality of life of people who have survived a stroke.<sup>4</sup> Regaining functional ability is therefore essential for the improvement in their quality of life. However, the impact of stroke can be multifaceted. Some survivors, regardless of whether they have satisfactory rehabilitation outcomes or mild residual impairments, may suffer from the ‘invisible’ sequelae like mental health issues, such as apathy, depression, anxiety, mental fatigue and sleep disturbance, which potentially diminish their quality of life but often being omitted.<sup>5–7</sup> Hence, the emotions, perceptions and subjective experiences with the illness and impairments may play a critical

role in the journey of stroke rehabilitation and require more attention.

Chronic illness or severe injuries bring forth changes in the survivors' embodied experiences, which means, the experiences of how survivors perceive the world through their bodies.<sup>8</sup> This concept originates from the term 'embodiment', which roots in phenomenology and conceptualises a body as a 'lived body' rather than an anatomical object.<sup>8</sup> Embodiment does not solely refer to the sense of locating and owning a body, but the assimilation of the various aspects of self-consciousness, which includes sensory, emotions and perception, into the physical body.<sup>9</sup> It is distinctive from the Western medicine approach that the body is an 'object', but rather conceptualises the body as a 'subject'.<sup>8</sup> Therefore, when adopting this approach to understand these illness experiences, apart from acknowledging the pathological symptoms or discomforts, the subjective illness perceptions and experiences of living with these symptoms are also considered.

People who have survived a stroke experience apparent changes in their bodies after the stroke, such as altered sensations, impaired limb function, uncoordinated movements and disrupted proprioception.<sup>10–13</sup> All these body alienations enhance the conscious perception of the body and may further create interferences in daily life, as healthy individuals usually perform bodily actions naturally and spontaneously without much-needed consciousness.<sup>14</sup> Living in a body with stroke-related impairments also alters survivors' social and personal lives, for example, causing disruption in their social routines and family lives.<sup>15–18</sup> Some survivors even struggle to return to work.<sup>18</sup> These experiences may further lead to changes in self-identity, psychological difficulties and poor post-stroke quality of life.<sup>19–21</sup> Since current medical and rehabilitation practices mainly conceptualise the body from a biomedical view,<sup>22–23</sup> stroke sequelae are attributed to biological or physical dysfunctions, and survivors' subjective experiences in their poststroke bodies are often neglected. Therefore, addressing this issue is crucial and much required for facilitating the rehabilitation process and promoting the overall well-being of people who have survived a stroke.

Encompassing the embodied lens in understanding patients' illness experiences has already been advocated for decades. In the medical field, biographical disruption is introduced to depict one's biography or self-identity being threatened by a chronic illness.<sup>24</sup> In some patients, the residual impairments increase their degree of dependency, which potentially interrupts their original daily routines and social roles, and further creates doubts in self-concept and uncertainties towards the future.<sup>24</sup> In psychology, health psychology also promotes the application of embodied health approach to discover how patients make sense of their experiences in an illness context.<sup>25–26</sup> Unfolding the patients' embodied experiences help rehumanise the current health services, which in turn helps to provide holistic patient care and optimise related interventions, such as improving

health outcomes and facilitating adjustment to bodily changes.<sup>25–28</sup>

Given that the experiences perceived through the post-illness body are crucial in determining the quality of post-illness life and adjustments to the post-illness body, it is necessary to understand the patients' embodied experiences. More importantly, including this perspective creates a more holistic view of supporting people who have survived a stroke to adjust and adapt to their poststroke bodies. While there are existing qualitative systematic reviews specifically on patients' experiences in rehabilitation and their adjustment after strokes,<sup>29–30</sup> this systematic review is the first of its kind that aims to synthesise the embodied experiences of people who have survived a stroke.

## METHODS

This qualitative systematic review followed the guidelines of the enhancing transparency in reporting the synthesis of qualitative research (ENTREQ).<sup>31</sup> The review protocol was preregistered with PROSPERO (reference number: CRD42020183125).

### Search strategy

The systematic literature search of five computerised databases namely, PsycINFO, PubMed, MEDLINE, CINAHL Plus and Cochrane Library, was first conducted in November 2019 and updated in March 2022. The keywords and syntaxes for the Boolean search in each database are attached as online supplemental file 1. To maximise the coverage and representativeness of the search results, the reference lists of the included studies were scrutinised to retrieve relevant studies that did not appear in the previous search.

### Study selection

Unlike synthesising the lived experiences of people who have survived a stroke which adopts a broader phenomenological perspective of lived experiences, this review specifically focused on the embodied experiences of people who have survived a stroke. 'Embodied experiences' refer to the subjective bodily experiences of how a person who has suffered a stroke lives in one's altered body to interact with the world under one's unique context.<sup>32</sup> In short, the experiences of how a person who has suffered a stroke makes sense of oneself, others and the world in one's poststroke body. Studies included in the systematic review specifically explored the lived experiences related to the bodies of individuals who had a stroke, the experiences that subjectively originated from their poststroke bodies. Studies which merely explored the general lived experiences of a person who suffered from a stroke but lack a bodily view of understanding their lived experiences were excluded. This review also only included the experiences of a person who had a prior stroke episode, ischaemic or haemorrhagic stroke. Studies of patients with a transient ischaemic attack were

excluded, as the corresponding effects of TIAs are relatively mild and temporary. Only articles published in journals were included. Posters or abstracts presented at conferences and unpublished master's or doctoral theses were excluded. For the study design, single-case studies were excluded, but cross-sectional and longitudinal studies were included. There were no restrictions on the age, gender or nationality of the informants. This review only included studies written in English.

### Data extraction

The first two authors were involved in the procedures of selecting articles and data extraction. The first author started the data extraction process with comprehensive searches in the selected databases and other resources, with all the results organised into EndNote. Any duplicate studies were screened and deleted. Irrelevant studies were then removed based on their titles and abstracts. The first author also examined the full texts of the remaining studies. Detailed reasons for the exclusion were listed. The second author helped cross-check the results of the full-text screening. Quality assessments were then performed independently by the first and second authors to ensure the quality of the included studies. The two authors then embarked on the data extraction process. A tailor-made Excel table was set up by the first author to record the pertinent details of each study, such as the aim of the study, the demographic information of the participants, the procedures of data collection and the methodological approach for data analysis. Next, the second author cross-checked the extracted details on the table. The findings of each included qualitative study were then extracted for data synthesis procedures. Any discrepancies between the first and the second authors were resolved through various meetings until a consensus was reached. The third author throughout supervised the complete process.

### Data synthesis

As the aim of this systematic review was to synthesise qualitative evidence, the data synthesis followed the thematic synthesis approach.<sup>33</sup> This approach involves three core stages—first, codes from the results of the included studies are created; second, descriptive themes based on the initial codes are developed; and third, analytical themes based on descriptive themes are conceptualised. The descriptive and analytical themes of this study were generated by an inductive process. The first and second authors were involved in the data synthesis procedures. After extracting the findings of the included studies, the first author searched for the content that depicted the embodied experiences of people who have survived a stroke and formed initial codes. Similar initial codes across studies were further categorised as initial themes. New initial themes were generated when a group of initial codes delineated new concepts and distinctive from the existing initial themes. NVivo software (QSR International, Burlington, Massachusetts, USA)<sup>34</sup> was used to perform the iterative process of organising the codes and themes. After the first author created an initial set of codes

and themes, meetings were held with the second author. The second author's role was to cross-examine the main idea and structure of the codes and themes. Before the meetings, the second author also identified related information from more than half of the included studies to provide constructive comments on adjustments or modifications during the discussions. Having undergone several meetings, the authors identified and reached a mutual agreement regarding the descriptive themes, analytical themes and hierarchical structure of the themes.

### Risk of bias assessments

This study applied the seven questions developed by Salter *et al* in 2008 to assess the quality of the included studies.<sup>35</sup> The seven questions assess the credibility and relevance of the studies, which are the two core criteria for appraising the quality of qualitative studies.<sup>36</sup> The seven questions were constructed based on the suggestions of two reviews appraising the quality of qualitative studies.<sup>36 37</sup> Five questions were set to evaluate the credibility of the studies based on the descriptions of sampling and data collection strategies, auditability, reflexivity, appropriateness in handling contradictory findings and fair dealing.<sup>35</sup> Two questions were set to document the relevance of the studies based on transferability and analytical generalisation.<sup>35</sup> While there are existing validated appraisal tools for qualitative studies, these tools were developed to assess the diverse types of qualitative studies and provide a relatively generic framework for evaluating the quality of qualitative studies.<sup>31</sup> The seven questions were considered appropriate and relevant to this current review as they were developed for a meta-synthesis that synthesised the lived experiences of living with stroke.<sup>35</sup> The assessed studies of the current review shared similar nature with those included in the previous meta-synthesis. Therefore, this tool could provide a more specific and comprehensive review in evaluating qualitative studies about lived experiences of people who have survived a stroke. This tool also covers critical elements in appraising the quality of qualitative studies. Regarding the process of conducting the quality assessment, the first and second authors individually conducted the quality assessment by responding to each question with 'yes', 'no' or 'partial'. After rating all the studies, the authors met and discussed their findings until they reached a final judgement and agreement. The included studies at least fulfilled two items in credibility and one in relevance. The results of the quality assessment are included in online supplemental file 2.

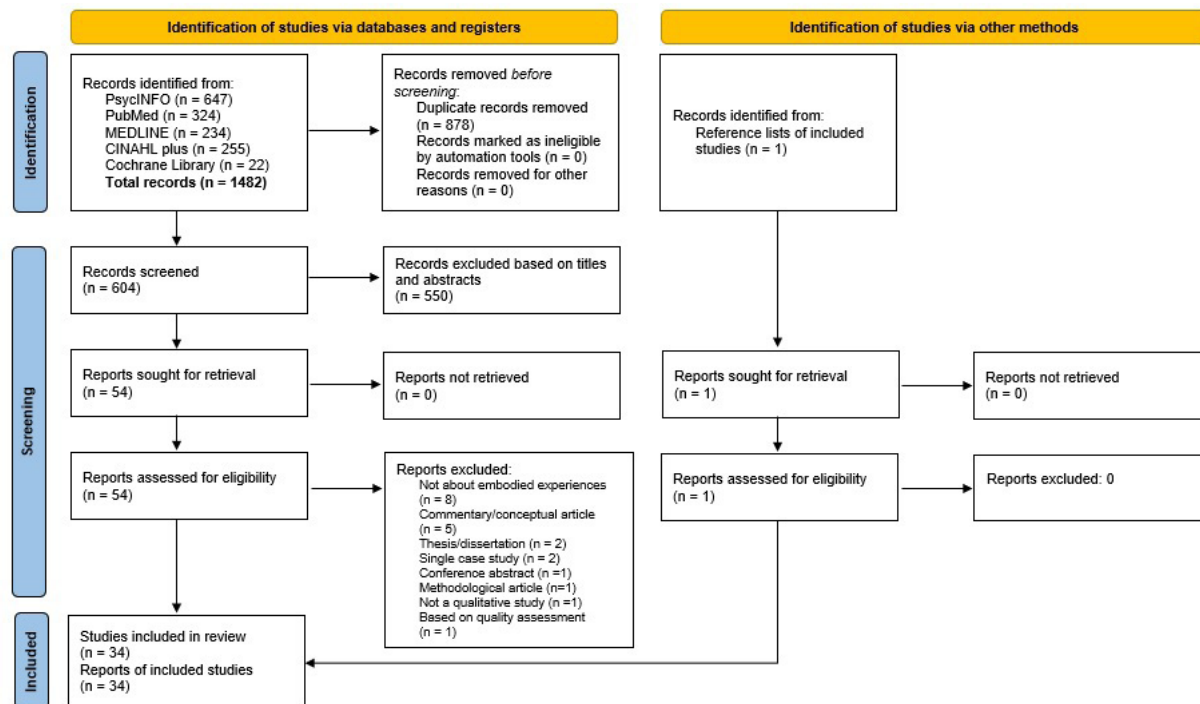
### Patient and public involvement statement

Neither patients nor the public was involved in this study.

## RESULTS

### Selection flow

The systematic search began with 1482 studies. After removing duplicate studies, the first author conducted



**Figure 1** Illustrates the process of selecting and identifying studies for this systematic review. It adopts the template of the PRISMA 2020 flow diagram for new systematic reviews, which included searches of databases, registers and other sources. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

the title/abstract screening on 604 studies. The first and second authors conducted the full-text screening on the remaining 54 studies. Twenty studies were excluded with a detailed reason after the full-text examination. One study was identified from the reference list of the included studies. The two authors subsequently conducted separate quality assessments on 35 studies. Eventually, 34 studies met the quality criteria,<sup>38–71</sup> and 1 study was excluded.<sup>72</sup> The Preferred Reporting Items for Systematic Reviews and Meta-Analyses 2020 flow diagram (figure 1) presents the process for selecting and identifying the included studies.

### Characteristics of included studies

This systematic review included 34 qualitative studies published between 1991 and 2021. The demographic characteristics of the included study are presented in online supplemental file 3. All included studies collected data via individual interviews with the patients who had a stroke. Eighteen studies (52.9%) conducted single interviews at one time point only,<sup>41 43 47 49 51–53 58 61–67 69–71</sup> 14 studies (41.2%) conducted repeated interviews<sup>38–40 42 44–46 48 50 54–57 68</sup> and 2 studies (5.9%) conducted both repeated and one-off interviews.<sup>59 60</sup> Regarding the data analysis approach, 19 studies (55.9%) adopted a phenomenological or hermeneutic approach,<sup>38–40 42 43 45 47 48 51 53–58 63 65 67 68</sup> 3 studies (8.8%) adopted a narrative approach,<sup>46 50 61</sup> 3 studies (8.8%) adopted an interpretative inductive or descriptive approach,<sup>64 69 70</sup> 2 studies (5.9%) adopted a grounded theory approach,<sup>66 71</sup> 2 studies (5.9%) adopted an ethnographic approach,<sup>44 60</sup> 1 study (2.9%) adopted

a deductive content analysis approach,<sup>52</sup> 1 study (2.9%) adopted a phenomenographical approach,<sup>41</sup> 1 study (2.9%) adopted both phenomenological and ethnographic approaches,<sup>62</sup> and 2 studies (5.9%) did not clearly state their methodological orientation.<sup>49 59</sup> Three overarching analytical themes were identified, namely, ‘disconnection between oneself, others and the world,’ ‘the transitional period: exploring and negotiating’, and ‘reconnecting with oneself, others and the world’. Each analytical theme was supported by the corresponding descriptive themes. The details of each analytical theme, the descriptive themes and selected quotations from the informants are listed in tables 1–3.

### Themes related to the embodied experiences of people who have survived a stroke

#### Disconnection between oneself, others and the world

This theme captured the stage at which survivors’ bodies were disrupted after the stroke episode, which also alienated their relationship with their bodies and surroundings.

#### Altered sensations and perceptions

Many survivors experienced numerous discomforts in the body and reported pain, paralysis, stiffness or numbness in affected body parts.<sup>40 44 49 50 53 54 59 67 70</sup> They also reported confusion in the size, weight, position and temperature of the impaired body parts.<sup>41 54 67 71</sup> Some survivors attributed the stroke-related impairments to the alteration of blood flow in the affected body parts.<sup>62</sup> Some survivors were also confused with their disrupted vision<sup>38 50 54</sup> or lower sensitivity to the surroundings.<sup>53</sup> The



**Table 1** Descriptive themes under ‘disconnection between oneself, others and the world’

Descriptive themes	Supporting studies	Selected supporting quotations
Altered sensations and perceptions	38–41 43 44 48–50 53 56 59 62 67 70	<ul style="list-style-type: none"> <li>▶ ‘It’s just an annoying feeling. It’s not a pain, like a heart attack or something. It’s not an ache-like. It’s a nervous feeling. Like you don’t know what to do with your hands or something like that. You really don’t know what’s happening. In my case it was just annoying.’<sup>50</sup></li> <li>▶ ‘I am numb in my skin and in some other deeper way that I cannot put into words. I cannot pinpoint precisely what it is—I just sense that something is very different.’<sup>54</sup></li> <li>▶ ‘the arm can feel very cold sometimes, I noticed between the two there’s a difference in temperature...the fingers... its constantly tingling...my little toe on the right side all the way...up to my ankle...can get hypersensitive and also, I feel as though my ankle’s broken...it just feels painful...I know it isn’t broken...and it’s not swollen, but it just gives me the wrong information.’<sup>67</sup></li> </ul>
Altered relationship with the body	38–59 64 67–71	<ul style="list-style-type: none"> <li>▶ ‘I don’t know what to do with this arm, perhaps it is best not to use it.’<sup>39</sup></li> <li>▶ ‘Quickly I learned to write with my left arm. I did all the work with my left arm... the other arm is only for decoration.’<sup>53</sup></li> <li>▶ ‘I don’t feel that I am a self [person] now. I have not found myself yet, because everything, all, has gone!’<sup>56</sup></li> <li>▶ ‘I can obviously move all my limbs, but I can’t really feel them, it’s like ...having Novocaine...it doesn’t feel like me anymore [laughs] ...it’s like(exhale/sigh)a parasite [laughs]...it is part of me but it’s not what it was...(pause) it’s who I am now...I don’t hate it, it’s just that that’s what it is...I don’t have to like it...(laughs).’<sup>67</sup></li> </ul>
Altered interpersonal relationships	38 40–47 52 53 55 57–61 63–68 70	<ul style="list-style-type: none"> <li>▶ ‘I can’t ... hang clothes on the line ... I’ve usually got to yell out to my son to come and give me hand. That makes me feel pretty small and frustrated.’<sup>43</sup></li> <li>▶ ‘I still feel like a freak. I just don’t like going anywhere where I’m well known and I feel now I’m not walking properly and you know it’s a funny feeling (Interviewer: yeah, what do you think other people are thinking?). Well, I don’t know, I don’t know that’s er I suppose perhaps that’s the thing, but er I mean I just feel to myself and think, oh poor thing you know and I don’t like to feel that I’m like that I mean er I still feel I want to be like I was before and I don’t know whether I will.’<sup>46</sup></li> <li>▶ ‘I lack confidence, especially when you have a problem walking. You feel as if you are trying to be the centre of attention; ‘Look at him he has got a walking stick’, although I am sure most people are not saying ‘look at him he has a walking stick’, but you feel that way.’<sup>58</sup></li> </ul>

disrupted perception of the outer world led to disorientation in the surroundings<sup>48 53 54 56</sup> and struggles in recognising objects<sup>53 56</sup> and using tools.<sup>39 43 54 56</sup> Survivors considered these distorted experiences to be hurdles in daily life,<sup>40 54 55</sup> and these experiences triggered negative feelings like fear, frustration, nervousness, annoyance and disappointment.<sup>39 50 54 56</sup>

#### Altered relationship with the body

Survivors realised their bodies were utterly different from before, and they had difficulties making sense of themselves in their new bodies. Many survivors described their bodies in a negative perspective, such as unreliable, unfamiliar, perplexed, restricted, uncontrollable

**Table 2** Descriptive themes under ‘the transitional period: exploring and negotiating’

Descriptive themes	Supporting studies	Selected supporting quotations
Facing daily struggles	39 40 42–51 53–57 59–64 66 70 71	<ul style="list-style-type: none"> <li>▶ ‘I remember when I was in my daughter’s car. She took me to the hospital. The doctor told me that I had to stay and couldn’t go home. They put me down but I didn’t lost conscience and I felt this hand sleepy. I couldn’t even talk, nothing, and I thought to myself, ‘Well, whatever God wants.’ I remember I was supposed to eat later on and use my right hand and I said ‘Oh God, I’m not going to be able to do this. Just let me do this.’<sup>50</sup></li> <li>▶ ‘Healthy people don’t think when walking, they can focus on many other things, thinking of something, planning something. I have to use all my concentration on walking. It’s not a matter of course, step by step in order not to tumble and fall. I have to use so much energy...’<sup>53</sup></li> <li>▶ ‘My biggest issue right now is that I need an hour to rest in the afternoons—it is a necessity to function the rest of the day and gain some energy. It [the tiredness] is a little bit better now, but without my hour of rest, I will not make it through the day. It is a disadvantage in my life.’<sup>64</sup></li> </ul>
Discovering new strategies	38–43 45–49 51 53–57 60 63–71	<ul style="list-style-type: none"> <li>▶ ‘I’ve had to learn to leave messages on my mobile phone in order to remember meet-ups and suchlike’<sup>38</sup></li> <li>▶ ‘The big thing is you can’t rush things. You’ve got to take your time, and if you take your time you find things start to happen and things become easier.’<sup>43</sup></li> <li>▶ ‘I have to command my arm. I use my arm a lot and I have to tell it; now I shall grasp something and now I shall lift it and so on, but this has become a routine too. I don’t think so much about it anymore.’<sup>55</sup></li> </ul>

**Table 3** Descriptive themes under ‘reconnecting with oneself, others and the world’

Descriptive themes	Supporting studies	Selected supporting quotations
A sense of cohesiveness with the altered body	38 40 48 49 51 53 55 63–65 70 71	<ul style="list-style-type: none"> <li>▶ ‘Right, I focus on my body now since I had [the stroke]. I’ve listened to my body more now than I had since I’ve had the stroke. I’m listening to it. Prior to the stroke I would listen to my body, but I now I’m in-depth with listening. Listening to the body, ya know?’<sup>49</sup></li> <li>▶ ‘There are no changes in my everyday activities, and I am doing the things that I did prior to my stroke. Basically, I am back to the person I used to be.’<sup>64</sup></li> <li>▶ ‘See, we walked all around the supermarket the other day, and I came home, and I was ‘as good as gold’.... It was just a matter of getting that self-assuredness back, to get the confidence back.’<sup>71</sup></li> </ul>
Regaining meaning in life in their altered bodies	38 47 63 64 69	<ul style="list-style-type: none"> <li>▶ ‘One must work with the tools one has been given; that is all you can ask for. Life’s not supposed to be dreary; it’s supposed to be fun. I do my best. One cannot ask for more! I keep doing things all the time.’<sup>38</sup></li> <li>▶ ‘The big change is that before I worked like a fool, it’s a big change and it was what was great about this.’<sup>47</sup></li> <li>▶ ‘To me, having a good life means that I as a person can do the things that I appreciate and love: go fishing, be with my family and my friends. Be with them in a way that is enriching to me—and hopefully for them too. Also, having a good life, most of all, is that we as a couple are doing well.’<sup>64</sup></li> </ul>

and non-responsive.<sup>39–47 49–51 53–56 58 59 64 67 69–71</sup> A sense of alienation or disownment was engendered towards their bodies.<sup>39 45–47 51 53 58 59 67 69–71</sup> Some survivors ignored the impaired body parts by treating those parts as being ‘disappeared’<sup>50 67</sup> or even deemed as an obstacle, a foreign or passive object.<sup>38 39 44 46 49 51 56 59 71</sup> Their sense of freedom, wholeness, orientation and integration were also compromised.<sup>44 57 71</sup> Some survivors also felt their sense of self was threatened due to the disrupted way of being or the internal conflict between the previous and current self.<sup>38 40 41 43 47 48 51 53 56–58 64 67 68 71</sup> They also expressed negative emotions, such as fear, anger, stress, grief, anxiety, isolation, depression, confusion and loneliness, which were related to their experiences of self-lost and the distorted relationship with the body.<sup>38–40 43 52 53 59 68–71</sup>

#### Altered interpersonal relationships

Survivors also stated that their altered body affected their relationships with others. They frequently reported losing their previous roles or identities in their families and workplaces.<sup>38 40–43 45 52 53 55 57–59 61 66 68 70</sup> Some survivors required intensive assistance in daily life and expressed that it was inevitable to depend on others.<sup>38 41 42 47 52 53 55 59 61 63 65 66 68 70</sup> The increase in dependency aggravated the feeling of vulnerability or guilt, causing trouble to the family, the loss of freedom and flexibility,<sup>52 53 55 70</sup> as well as disruptions in relationships.<sup>47 53 58 63 70</sup> Most survivors were forced to withdraw from social activities due to fatigue and poor ambulation.<sup>38 45 53 55 59 60 63 64 67 68 70</sup> The residual impairments also prevented them from accessing external resources.<sup>60</sup> Survivors also deemed their bodies as a barrier when engaging with others because of the use of walking aids, awkwardness or abnormalities of the bodies and uncontrolled behaviours, such as non-fluent speech, weird postures, awkward movements, paralysed facial expressions and sudden mood fluctuations.<sup>38 44 46 53 55 57–59 68</sup>

They were also worried about the social gaze or being stigmatised.<sup>46 53 65 68</sup> Misunderstandings were possibly created when they failed to manage themselves to fit into social norms, for example, they could not use tableware properly or follow the etiquette for stairs.<sup>46 60 68</sup> They also found it complicated to seek understanding from others, particularly when some of the stroke sequelae were invisible, such as aphasia or numbness.<sup>53 59</sup>

#### The transitional period: exploring and negotiating

This theme described the survivors’ experiences in finding multiple solutions to attune with their poststroke bodies.

#### Facing daily struggles

To restore their participation in daily life, survivors tried reaching out and resumed their routine life. They perceived the experiences of living in the ‘new’ body to navigate a previously familiar environment, like the home and workplace, or perform usual routines as different than before.<sup>40 42 45 48 57 59 60 71</sup> As the body acted differently, the survivors required extra mental effort to guide the body, such as continuously paying attention or fragmenting each movement into small steps.<sup>39 42 43 49 53–56 59 63 71</sup> Extra time was therefore needed to accomplish various daily tasks, particularly household chores and self-care routines.<sup>43–46 48 55 66 70</sup> Survivors also expressed their exhaustion in paying extra concentration on every move,<sup>39 47 48 51 53 55 57 61 63 64</sup> and the persistent feeling of fatigue might also deprive them of returning to their normal lives.<sup>45</sup> Facing these hardships, some survivors found anchoring to religion helped cultivate healing effects or develop their inner strength and acceptance.<sup>49 50 62 71</sup> Other survivors also tried to accept the current stable situation and redefined their recovery goals to alleviate discomforts or adapt to the restrictions

in life, as it might be unrealistic to return to the previous state.<sup>45 47 59</sup>

### *Discovering new strategies*

Despite experiencing difficulties in daily life, survivors developed new strategies to cope with the altered bodies. Some survivors tested or reappraised their bodies to understand their condition.<sup>46 48 49 66 70</sup> They also put immense effort into rehabilitation training to restore their bodily functions as much as possible.<sup>40 45 48 53 67 68</sup> They continuously created, practised and experimented with new solutions to find the most suitable way for themselves.<sup>38 43 48 57</sup> New strategies included observing ‘normal’ people, working at a slower pace, relearning how to use the body little by little, being organised with planning and regular procedures, communicating with oneself and the altered body, and modifying the existing methods of using the body.<sup>38 39 42 43 48 49 53 55 56 60 63 65 70</sup> Other survivors also incorporated assistance devices as part of their daily routines,<sup>53 55 56 65</sup> but they also worried about the deterioration in physical abilities due to over-relying on aids.<sup>60</sup> They also became used to being assisted by others.<sup>42 47 48 55 68</sup> Some survivors occupied themselves with a more regular schedule, engaged in several fixed tasks and reclaimed the ability to do previous usual chores, which helped enhance the sense of normality.<sup>48 49 51 54 66</sup> Moreover, gaining knowledge and cultivating positive attitudes were vital in making sense of their experiences and getting through the transitional stage.<sup>41 43 47 49 64 68 69 71</sup>

### *Reconnecting with oneself, others and the world*

This theme highlighted that poststroke embodied experiences could still be positive and meaningful after reaching the balance of one’s expectations and participation in life.

### *A sense of cohesiveness with the altered body*

After spending time in physical rehabilitation, some survivors experienced improvements in the body, which included a reduction in discomfort and a restoration of the ability to perform specific tasks—for example, involvement in household chores.<sup>38 51 55</sup> They were more hopeful when making progress<sup>40 48 70</sup> and acknowledged the impaired body as more than just a passive object.<sup>53</sup> They also felt a sense of control, freedom, familiarity, spontaneity or wholeness over the body when reclaiming their ability to perform some previous daily activities.<sup>48 49 51 55 65 71</sup> All these experiences contributed to restoring the sense of independence and normality.<sup>51 64</sup> Furthermore, some survivors discovered that their sense of self could also be maintained or even transformed into a new sense of self despite experiencing residual restrictions in the body.<sup>38 63 64 71</sup>

### *Regaining meaning in life in their altered bodies*

It was still possible to search for purpose in life after the stroke in the new poststroke body. Some survivors realised that living in their poststroke bodies allowed them to replace their lives, reflect on themselves and elicit new

insights into their lives.<sup>47</sup> Meaningful connections and a sense of belonging could also be re-established with people, like family, friends and other stroke survivors, through the poststroke bodies.<sup>47 64</sup> Re-entering the workforce or engaging in new activities further helped reinforce meaning in life as they could contribute to society in their altered poststroke bodies<sup>47 63 64 69</sup> and discover new physical capabilities.<sup>38 47</sup> They also experienced better management in life as they started achieving an equilibrium between the competencies of the poststroke bodies and participation in life.<sup>63 64</sup>

## DISCUSSIONS

This review systematically examined 34 qualitative studies on the embodied experiences of people who have survived a stroke. The core objective was to synthesise the embodied experiences of people who have survived a stroke, the experiences of how they make sense of themselves, others and the world in their poststroke bodies.

The results displayed that the embodied experiences of people who have survived a stroke were significantly disrupted. The embodied experiences progressed from feeling disconnected to reconnecting with the body, others and the world. In the beginning, there were numerous mismatches and misalignments between the body and mind of the survivors as they tried to retain the previous habituated patterns and lifestyles with their altered bodies. The feeling of disconnection was developed as the body did not meet one’s expectations. A majority of survivors experienced uncomfortable sensations and restrained movements. These discomforts further modified how they interacted with their bodies and induced various struggles to use the body in daily tasks. As their bodies became alienated, the survivors perceived changes in social interactions and interactions with the environment. Despite encountering bodily struggles, some survivors managed to overcome their body limitations to reach out and resume regular routines. Some of them also regained part of their physical abilities through rehabilitation. The process of re-experiencing how to use one’s physical body, like experimenting on one’s ability, communicating with oneself and testing new strategies, could be viewed as the transitional stage. Furthermore, some survivors perceived themselves as less impaired once they experienced functional improvement or invented new ways of living in their poststroke bodies. They could then redevelop a new sense of self, recultivate the sense of cohesiveness with the body and re-engage with previous or new meaningful activities in their poststroke bodies.

The process of adapting to, getting familiar with and reintegrating into the poststroke body can be termed ‘reembodiment’.<sup>55</sup> The body is no longer an ‘impaired’ body but a ‘new body’.<sup>38 55</sup> Furthermore, experiencing re-embodiment may not be entirely related to the severity of the physical impairments. Reports of experiencing an altered body were found in survivors with and without

palpable physical impairments.<sup>46 53 55 58 68</sup> Researchers have also suggested that recovery is not merely defined as living without all the pathological symptoms and impairments but adapting to new ways to perceive and live within one's unique context.<sup>73 74</sup> Additionally, the review demonstrated that restoring functional abilities might contribute to the progress of approaching re-embodiment. Regaining physical abilities helps gradually enhance the familiarity and normality of the poststroke body.<sup>48 55</sup> Training back the strength and endurance of the body also facilitates social participation, improves mood and optimises quality of life.<sup>75</sup> Overall, it remains unclear how people who survived a stroke can overcome all these struggles or how much time and effort they need to re-embody their bodies.

The intensity of disruption in each individual's embodied experiences also varied. Each individual's pre-illness embodied experiences have been suggested to affect how one perceives the illness-related disruption.<sup>76</sup> For instance, older adults may experience relatively fewer disruptions because they may have other commodities and higher readiness to live with physical limitations.<sup>77</sup> Similarly, age, comorbidities and knowledge of stroke are significant factors that minimise the perceived level of disruption after stroke.<sup>78</sup> For example, equipping with more stroke-related knowledge helps promote readiness in facing the influences of stroke on the body and daily living and enables one to feel less disrupted.<sup>77</sup> This current review illustrated a similar trend and implied that embodied experiences are unique to each survivor and will constantly evolve during the trajectory of stroke rehabilitation. Regardless of the time spent living with the impairments of stroke, one could immerse in the loss and sadness and still struggle with the ruptures between the body, mind and surroundings. Conversely, one could also be optimistic and creative about coping with this situation and cultivating realignment between oneself and the body.

Experiencing re-embodiment may be a critical turning point for people who have survived a stroke. It indicates that they are evolving from grieving their loss and suffering from bodily discomfort to finding new ways to communicate with the body and understand how best to use it, even though there are residual physical impairments. Therefore, it is worth exploring how to facilitate people who have survived a stroke in re-embodiment. In this aspect, short interviews or screening assessments on their embodied experiences are highly recommended. There are existing scales to measure the experiences of living in the body, for example, the Experiences of Embodiment Scale<sup>79</sup> and the Body Perception Disturbance Scale.<sup>80</sup> Health professionals may use these measurements to understand the embodied experiences of people who have survived a stroke for prescribing treatments or designing person-centred interventions to address each survivor's needs. Nonetheless, as both scales have not been used in the stroke population and the Body Perception Disturbance Scale is also specially designed

for patients with Complex Regional Pain Syndrome, applying these measurements to patients with stroke requires prior adjustment and validation. Besides, preliminary findings have shown some therapeutic approaches that enhance one's awareness of the body, like Basic Body Awareness Therapy,<sup>81</sup> may help people who have survived a stroke improve their posture and movements as well as induce feelings of harmony and peacefulness in the body.<sup>82</sup> Further investigations are needed to explore if such approaches can assist survivors in adapting to their poststroke bodies.

## STRENGTHS AND LIMITATIONS

This is the first qualitative systematic review that provides an overview of the embodied experiences of people who have survived a stroke. These subjective experiences are critical because although the functional ability has been restored, survivors may still experience alteration of their bodies from their perspective. Moreover, this systematic review calls attention to understanding the illness experiences from a subjective perspective. These experiences are as important as curing pathological symptoms and physical impairments during rehabilitation. Nonetheless, this review also has several limitations. First, some included articles did not provide adequate demographic characteristics under each informant's quotation; hence, this systematic review could not further perform subgroup analyses to explore the relations between these factors and the corresponding embodied experiences. Second, most reviewed studies only included informants with good verbal and cognitive abilities. Survivors with severe cognitive or verbal deficits may encounter barriers in expressing their experiences and may have different embodied experiences. Third, the sample size of some included studies was relatively small, even for qualitative studies, that is, 4–6 participants, which may impact the studies' trustworthiness and generalisability. Fourth, the appraisal tool adopted in this review has not been formally validated, which may affect the representativeness of the results of the quality assessment of included studies. However, this tool was still adopted as it was used in a previous meta-synthesis about lived experiences of patients with a stroke that shared a similar context with the current review. Fifth, this systematic review only included published literature written in English. Relevant grey literature and studies published in other languages were not included in this review.

## FURTHER STUDIES

Further studies are necessary to explore how people who have survived a stroke define and approach re-embodiment. Additionally, survivors with different levels and types of impairments may have different embodied experiences. Further exploration may help healthcare professionals develop strategies to support people who have survived a stroke to live in their altered bodies, adapt to their lives



after stroke and—eventually—help them regain meaning in life. Quantitative studies are also desired to confirm the relationships between re-embodiment and the survivors' overall well-being and quality of life. As 're-embodiment' involves reconnecting the mind and body, various mind-body interventions, such as mindfulness, may play a significant role. Previous research on yoga practice for people who have survived a stroke has demonstrated particularly positive outcomes for reconnecting the body.<sup>83</sup> Arts-based interventions are also included as a psychotherapeutic approach to connecting the mind and the body. The arts-making process in arts-based intervention serves as an avenue for expression and reflection because different art modalities stimulate diverse sensations and allow individuals to discover the connections between bodily sensations and emotions.<sup>84 85</sup> These experiences help cultivate insights, personal strength, self-identity and life worthiness.<sup>84 86</sup> A recent systematic review of the relationship between mind-body interventions, psychological stressors and quality of life in people who have survived a stroke has also recommended further studies to adopt a rigorous research design, such as randomised controlled trials with a mixed-methods design, to evaluate the effectiveness of mind-body interventions on elevating survivors' psychological condition.<sup>87</sup> Further studies are also needed to investigate how culture may or may not affect the perception of the bodies, as existing published studies were predominately conducted in the Western context, with only three studies conducted in Asia.<sup>52 62 68</sup> This is important because perception and feeling towards the body are culturally bounded<sup>88</sup>; for example, the 'yin' and 'yang' concept of the body and the 'qi' and 'blood' systems are unique to Eastern culture, which may further affect an individual's perception of their body. While this qualitative systematic review only reviewed the embodied experiences of people who have survived a stroke, further studies may explore the embodied experiences of patients with other chronic illnesses that induce changes in their physical bodies, such as cancer and Parkinson's disease. Understanding their embodied experiences may help optimise their post-illness quality of life and well-being.

## CONCLUSIONS

Inevitably, an individual's embodied experiences were altered by a stroke episode. Survivors experienced uncanny embodied experiences in the realms of sensations, feelings and perceived relationships with the body, as well as relationships with others and the external environment. While not every survivor considers these changes as disruptions in life, the body is inarguably different. Although the body may not return to the prestroke state, rebuilding the intimate connection with the body and regaining relationships with others and the world is still possible with progress in physical rehabilitation and, more critically, with an appropriate adjustment to their perceptions of the new body. Further research may investigate how to support people who have survived a stroke in re-embodiment of their bodies. Mind-body interventions, as

well as other non-pharmacological approaches, may also be viable choices.

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