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Experiences of returning to work, and maintaining work 7 to 8 years after stroke - a qualitative interview study

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ABSTRACT

Objective: To explore how persons experienced return to work and their work situation 7 to 8 years after stroke.

Design: The study had an explorative qualitative design with individual interviews. The data analysis was inductive thematic and two researchers cooperated during the analysis process.

Participants: The study population included five women and eight men who had a stroke during 2009-2010, received care at the Sahlgrenska University Hospital in Gothenburg, Sweden, and returned to work after stroke, a heterogenic sample based on age, occupation, stroke severity, and time to return to work.

Results: The analysis led to four themes revealing that participants were motivated to RTW while struggling with impairments in the RTW process. The RTW process evoked mixed feelings of worry and grief over lost functions but also acceptance and gratitude for being able to work. Although maintaining work 7 to 8 years after stroke, most were restricted in some way. Fatigue and cognitive impairments meant having to set limits, omit work tasks, and rest at work, but also rest during free time and omit social activities in order to manage work life. Participants avoided work related stress if they could because of aggravated symptoms and/or fear of a new stroke. Support from supervisors and colleagues was often crucial for a sustainable work situation but when not supported or even discouraged at work, it could mean a lonesome struggle to endure impairments and stress related symptoms while pushing their limits to manage work demands.

Conclusion Maintaining work can be a continuous struggle with invisible impairments many years after stroke. Strategies for managing work are dependent on each individual work situation, where support and understanding at work seems to be crucial for a sustainable work situation.

Strengths and limitations of this study (bullet points)

- The focus of this study was the perspective of persons who had worked for many years since their stroke, but apart from having this in common, they represented a wide range of occupations, stroke characteristics, and social backgrounds, gave rich interviews and contributed with experiences of maintaining work life in the long run after stroke.
- The patient perspective was integrated throughout the study as the interview guide was developed in cooperation with a patient representative from the Swedish Stroke

Association, a pilot interview was conducted, and further in the analysis process the participants were invited to a meeting to discuss and give feedback on the results, which gave credibility to the interpretations.

- A limitation of this study was that it only considered the perspective of persons who had RTW after stroke, and not included other stakeholders in the RTW process.
- This study was performed in the Swedish context and the transferability of results to other cultural contexts needs consideration.

INTRODUCTION

Return to work (RTW) is commonly referred to as the event when resuming work after a period of sick leave although a broader view has been suggested to include the whole RTW process, from initial work disability to reaching ones' full potential at work.[1] In Sweden, 25-30 000 people suffer a stroke each year, of whom 20% are of working age, an age group in which stroke has become more common in recent years.[2] The reported RTW rate between one to three years after stroke varies globally between 50 to 74 percent,[3-7] of which two Swedish studies found a RTW rate of 74%.[6, 7] In Sweden, employers have the most explicit responsibility of rehabilitation concerning their employees´ RTW, although shared with health care, the Social Insurance Office (SIO) and the Employment Agency (EA). Employers are obliged to adapt work tasks, working hours, start work trials, and make technical adjustments, though they are not forced to expand or create new work tasks. Common predictors for RTW in non-communicable diseases have been found to be higher socioeconomic status, higher self-efficacy, and positive expectations of recovery, less severe illness, better RTW coordination, and multidisciplinary interventions including the workplace.[8] For stroke, minor stroke severity and good self-rated health have been reported to be predictors for RTW.[4] Predictors for no RTW have been reported to be dependent at discharge,[7] low functional status 1 year after stroke,[6] degree of residual disability,[9] sick leave prior to stroke,[7] unemployment,[10] low socioeconomic status,[6] being an immigrant,[10] comorbidities,[10] older age,[5] and being female.[3]

A recent meta-synthesis of qualitative studies on RTW after stroke summarized important factors related to rehabilitation services (availability, accessibility, and appropriateness), the person (impairments, coping, adaptation, and motivation), and the workplace (demands, adaptations, disability management, work climate, and social support).[11] Another qualitative study found that awareness of invisible impairments generated support from employers and colleagues at work and a positive work experience, whereas the opposite presented a large barrier for RTW.[12] A qualitative study suggested the importance of a coordinator for communicating information between stakeholders in the RTW process.[13] Work has been found to be of importance for well-being and life satisfaction after stroke,[14] and RTW can be seen as a strive for normality,[12] and although many studies have investigated factors influencing return or no return to work after stroke, few have studied experiences of working in the long run after stroke.

The aim of this study was to explore experiences of returning to work and maintaining work seven to eight years after stroke.

METHODS

Study design

This is an explorative qualitative study using individual interviews and an inductive thematic analysis.[15] The COREQ guidelines for reporting qualitative research were used.[16] The study was approved by the Regional Ethics Committee in Gothenburg, Sweden, on June 5th 2013 (Dnr: 400-13). Oral and written information was given to all participants and they signed an informed consent form.

Participants

Participants were identified in the Extended Stroke Arm Longitudinal study at the University of Gothenburg, SALGOT-extended. The inclusion criteria were; having suffered an ischemic or hemorrhagic stroke in the years 2009-2010, having received care at the Sahlgrenska University Hospital in Gothenburg, Sweden, residing in the Gothenburg urban area, being of working age (18-64), and having RTW after stroke. Eighty-two persons were potentially eligible and a letter with information of the study was sent out to a purposive sample of 37 persons to achieve a heterogenic study population based on age, gender, occupation, stroke severity, and time to RTW. The letter was followed up by a telephone call to confirm participation and to schedule interviews. If a person was not reached by telephone, another letter was sent out encouraging the person to make contact if they were interested in participating. Fourteen persons agreed to participate, but one was excluded due to not having RTW after stroke. At arrival, the participants were asked to complete a form about demographics and employment which is presented in Table 1 together with clinical characteristics retrieved from medical charts.

Table 1. Demographic and clinical characteristics of the study population

	Study population (n=13)
Age, mean years (min-max)	50 (39-64)
Gender:	
Female/Male	5/8
Country of birth:	
Sweden	10
Outside Europe	3
Current living conditions:	
Living alone	5
Living with partner/ -and children	3/5
Type of stroke:	
Ischemic stroke	9
Intracerebral hemorrhage	4

Stroke severity: Mild Moderate Severe	 10 2 1
Stroke localization: Right hemisphere Left hemisphere Bilateral Not specified	 4 3 1 5
Discharged from the stroke unit Discharged home/ to rehab center	 9/4
Education: ≤ 9 years 10-12 years > 12 years	 5 3 5
Occupations	Accountant Assistant nurse Civil Engineer Cleaner (n=2) Commander on ferry Dentist Economist Police inspector Production worker Service technician Terminal worker Vehicle fitter
Work related characteristics	
Time to RTW (100% sick leave)	2 months – 2 years
Same employer as before stroke Lost job before RTW Lost job after RTW	11 1 1
Percent of employment 100% 75% 50%	 10 2 1
Employment Employed in public sector Employed in private sector Self-employed Employed in sheltered work	 5 5 1 2

Data collection

Individual, face-to-face interviews were conducted by the first author (AP, PhD, Physiotherapist, woman) using a semi-structured interview guide with open-ended questions. The interview guide included two main questions with supplementary questions concerning 1) experiences of returning to work after stroke and 2) experiences of working 7-8 years after stroke. The interview guide was discussed and revised in cooperation with a patient representative from the Swedish Stroke Association and was first tested in a pilot interview. Thirteen interviews were performed during April to September 2017, three took place in the participants' homes and ten at the rehabilitation medicine research unit facilities. By request of one participant, the interview was conducted in the presence of a next of kin who clarified answers due to language difficulties. The duration of interviews ranged from 40 to 90 minutes. All interviews were audio-recorded and transcribed verbatim by the first author (AP). Data saturation was achieved after 13 interviews.

Data analysis

The transcribed interviews were analyzed by inductive thematic analysis.[15] First, the transcribed interviews were read and re-read by two of the authors (AP and MT, PhD, medical social worker, woman) separately to familiarize with the texts and to obtain a sense of the whole. In this process, initial codes were noted separately by the two authors. Second, the authors coded the interviews together and searched for potential themes. The themes were then reviewed and refined by the two authors together and differences were discussed until consensus was reached, with the aim of enhancing the credibility of the analysis. The analysis process moved continuously back and forth between the whole and parts of the text to ensure the validity of the themes in relation to the data set. The third author (KSS, Professor, MD, stroke specialist, woman) contributed with stroke specific knowledge. The study participants were invited to a meeting to hear the results and to discuss the interpretation with the authors. An example of the coding process is provided in Table 2.

Table 2. Example of the coding process

Data extract	Code	Theme
(my boss says) "I see that you are tired, you need to rest. You need a break. Sit down there in the corner in my recliner and rest, I can see it in your eyes that you need a break, so I'm 'shutting you down' (like a machine) a little and I'll keep working."	Acknowledging symptoms and encouraging rest at work	Social support for a sustainable work situation

RESULTS

Four themes were identified; *motivated and RTW while struggling with impairments*, *mixed feelings in the RTW process*, *still at work though restricted* which includes two sub-themes, and *social support for a sustainable work situation* (Fig 1). The themes are illustrated with quotes from the participants.

Insert figure 1 about here

Table 3. Impairments affecting work initially in the RTW process and 7-8 years after stroke, as expressed by participants.

Initial impairments	**Residual impairments**
Altered mental functions	
Disorientation in time	
Disorientation in space	
Lack of initiative	
Difficulties concentrating	Difficulties concentrating
Difficulties multitasking	Difficulties multitasking
Difficulties processing information and impressions	Difficulties processing information and impressions
Difficulties with numbers and letters	
Memory difficulties	
Depression	
Fatigue	Fatigue
Altered sensory functions and pain	
Sensitivity to sound	
Sensory loss and alterations	
Headache	Headache
Balance difficulties	Vertigo and balance difficulties
Altered neuromusculoskeletal functions	
Muscle weakness on one side of the body	Muscle weakness on one side of the body
Coordination difficulties	
Altered voice and speech functions	
Losing volume of voice	

Motivated and returned to work while struggling with impairments

Participants described a wide range of impairments that initially affected RTW (Table 3).

Full time sick leave was prescribed for all participants and lasted between two months up to two years. Motivational factors for returning to work were an urge to leave the role of sick person behind, regaining a meaningful daily activity, strong work morals and work identity, economic needs, and a strive for normality.

" The best rehabilitation for me has been starting to work again and getting away from the being sick part, and I wanted to get out and, like, meet people…. It was a way to start to function normally again." Man, 39 years

All participants returned to work gradually in an individually adjusted pace and everyone returned to their previous job, except one who found a new full-time job. The RTW was sometimes too early or the gradual escalation was sometimes too rapid. This was related to high ambitions in combination with impairments and resulted in setbacks which forced a backwards step in the RTW process. This was frustrating, but manageable when focusing on striving forwards in the RTW process. Experiences of RTW at just the right pace or later than appropriate were also reported. They were hindered by doctors, work supervisors, or family members, raising feelings of disappointment or discouragement, but also of being cared for.

"they warned me that I'd be fatigued and stuff like that, but I thought I could handle it quite well with the gradual steps that I took. And there were planned rest days… And then the doctor said: people manage to start working pretty well, but it's important that you have longer recovery times, that are not broken up." Man, 58 years

In the RTW process, individual adaptations of work time, work tasks, and the work environment were performed in partnership with the employer.

"He's given me a good room and good nurses and good support, so like, a lot of stuff around me, he has been up for making sure I have calm surroundings and a stable room and not need to change between a bunch of different nurses, I have the same ones, so he's been very supportive in that way…" Woman, 57 years

Work demands were adjusted by refraining from works tasks and responsibilities. Some described no need for adaptations and were content with their work demands.

Mixed feelings in the RTW process

Uncertainty about consequences and prognosis of recovery raised worries about the future, including work life. Speculations about whether impairments were age- or stroke related were expressed. Expectations of a fast recovery sometimes led to disappointment later when still struggling with impairments, or to satisfaction when the recovery rate turned out as expected. Some had been told by doctors that they would fully recover but when still struggling with impairments and work tasks 7-8 years after stroke they wondered how and when that would happen. However, gratitude for functioning well despite stroke when considering how life might have turned out was expressed; they had been given a second chance in life and could work.

"I'm happy to be able to work 75%, because I had a large stroke, so the idea that I'm able to work at all, that's completely amazing." Woman, 57 years

Acceptance of impaired functions as well as a more relaxed attitude towards work life were expressed. Participants described satisfaction with regained functions, but also frustration and grief over lost functions and disappointment at having been deprived of career opportunities.

Still at work though restricted

Seven to eight years after stroke, impairments were less obvious than initially post stroke, though most participants had impairments that still interfered with work (Table 3).

Setting limits

Setting limits for colleagues, patients, and customers to create opportunities for rest and undisturbed work was one strategy used to manage work demands. It was hard, and time consuming to shift focus and get back on track with their own work tasks after being disrupted by others, forcing participants to set limits for interaction with colleagues in order to focus on their own tasks. Limiting ambition was a way to avoid fatigue, this could mean delegating work tasks or accepting a more subordinate work role. When demands on multitasking and information processing were too high, this could lead to confusion, insecurity, and refraining from work tasks. Difficulties setting limits at work were experienced when expressed needs were not heard by supervisors or colleagues. Sometimes, participants chose not to participate in social activities at work due to fatigue, forced to focus on work tasks and nothing else.

"Some days are a lot, and you get interrupted the whole time during your breaks and stuff…though I try and work around that by not going on break when everyone else does. Sometimes I've thought that my brain needs to rest a little, it's fun to sit and chat with the others so I'm part of the group, but some days I feel… I want to take the opportunity to have a break when the others have gone so I can have a little bit of peace." Woman, 48 years

When trying to keep up appearances to compete with colleagues, one participant avoided setting limits. However, some found it easier to set limits now than before their stroke, they mentioned being able to stand up for themselves and knowing more about their rights.

Independent work was described to allow for work at their own pace, providing opportunities to prepare and plan work according to their own functional level. Fatigue was described as a dominant impairment that was coped with by taking pauses at work, which was allowed for at some workplaces but not at others.

"then there's the fatigue, if I'm going to have a more complicated meeting with a customer, or if I need to have a wage renegotiation meeting or performance review, I always have them in the morning. I always plan them for the mornings, because in the afternoon I get more fatigued, unfortunately." Woman, 45 years

Gaining insight post stroke into the importance of taking care of their own health sometimes led to prioritizing physical exercise in order to be able to function better at work. But finding the energy for exercise was sometimes impossible when they were stuck in the vicious circle of fatigue and work demands. Some described exercising less than before the stroke, due to the fear of a new stroke. Participants described an excessive need for rest, before and after work. Spare time activities were often neglected due to lack of energy and were replaced by rest and sleep to manage work.

"Before I had my stroke I had an allotment, so when I was finished at work I'd go and dig and do some work there. I rode my bike there. Now I just can't manage it… I feel that things are different to before, but I want to live like that, like, I don't want to push the limits, I want to try and live the way I am able to." Man, 59 years

Work related stress

Work demands of being constantly available to customers, patients, or colleagues and a competitive work environment, lack of control of workload, and irregular inflow of work created stress. Also, having to adjust to changing work schedules, being forced to work overtime, or having to manage the same work demands as before stroke were stressful.

When exposed to stress at work, participants described having symptoms like the ones they had at stroke onset, such as sensations of numbness, tingling, and headache, which gave rise to the fear of having a new stroke.

"So every time you get a headache you start to think negatively, think if it's another thing like that that is happening (a new stroke) … before I had the stroke, you could say I was very stressed out. But

now I don't stress as much. I think, nah it will take the time it takes and not stress too much, it's just that way. So, like at work right now, you work but not as intensively as you did before, and you have to think about your own health too." Man, 46 years

The participants tried to avoid work related stress but when this proved impossible, one started his own business to regain control over his workload. Others were forced to stress at work and endured recurrent symptoms such as headache, fatigue, vertigo, or high blood pressure and felt trapped because of economic needs or were too exhausted to change jobs.

Social support for a sustainable work situation

Participants felt looked after and privileged when supported by their supervisor. A supervisor could advocate work task adaptations, acknowledge symptoms, and encourage rest at work, or could accept flexible working hours.

(my boss says) "I see that you are tired, you need to rest. You need a break. Sit down there in the corner in my recliner and rest, I can see it in your eyes that you need a break, so I'm 'shutting you down' (like a machine) a little and I'll keep working." Woman, 48 years

Some participants did not feel supported by their supervisor, who ignored them and their needs which created a strenuous work situation. One supervisor gave mixed signals, both being supportive and setting unreasonable demands at the same time. One participant had been discouraged by the supervisor at a rehabilitation meeting but stood up against the supervisor and gained support that way. One participant felt actively discouraged by the supervisor and experienced that the supervisor tried to force them to resign.

And she, my boss, doesn't accept the doctor's certificate but it's, I don't know what to say, they're against me…In two weeks I'm going to work nights, but I…they want me to take the week off unpaid. Last time it was a late shift I took holiday leave…" Man, 59 years

Participants said that it felt safe to return to the same work team, they got along well with colleagues when they could communicate openly and joke about their symptoms at work. When impairments did not interfere with work, some appreciated being treated like anyone else, but when impairments affected work, some appreciated to be relieved of work tasks, and receive social support from colleagues.

Societal support could mean assistance from a labor union, the Swedish Social Insurance Agency, or the Employment Agency in the RTW process. One could feel supported but also exposed by contact with these authorities.

DISCUSSION

Findings

The analysis led to four themes revealing that participants were motivated to RTW while struggling with impairments in the RTW process. The RTW process evoked mixed feelings of worry and grief over lost functions but also acceptance and gratitude for being able to work. Although maintaining work 7-8 years after stroke, most were restricted in some way. Fatigue and cognitive impairments meant having to set limits, omit work tasks, and rest at work but also rest during spare time and omit social activities to manage work life. Participants avoided work related stress if they could because of aggravated symptoms and/or fear of a new stroke. Support from supervisors and colleagues was often crucial for a sustainable work situation, but when not supported or even discouraged at work, it could mean a lonesome struggle enduring impairments and stress related symptoms while pushing their limits to manage work demands.

Strengths and limitations

A strength of this study was that the interview guide was developed in cooperation with a patient representative from the Swedish Stroke Association and a pilot interview was conducted. Another strength was the heterogeneity of the study population, representing a wide range of occupations, stroke characteristics, and social backgrounds. The participants gave rich interviews and contributed with a wide range of experiences. In the analysis process, two authors with different professional backgrounds (medical social worker and physiotherapist) coded separately and then jointly, ensuring a thorough coding process with the aim of capturing all relevant data. When developing themes, open discussions on coherency, consistency, and distinctiveness led to consensus which contributed to the credibility of the study.[15] The third author (MD, stroke specialist) contributed with stroke specific knowledge. When invited to a meeting, participants gave feedback on the results which were taken into account and gave further credibility to the interpretations. A limitation of this study was that it only considered the perspective of persons who had RTW after stroke, and not included other stakeholders in the RTW process. Also, this study was performed in the Swedish context and the transferability of results to other cultural contexts needs consideration.

Comparison with existing literature and guidelines

In this study, we gained a profound perspective of RTW from the view of persons with stroke who had managed to RTW and stay at work for many years. Work seemed to be important to the participants, who were all motivated to RTW. This can be interpreted in the light of previous findings stating work as an important part of life, identity, and social context.[17] Being motivated to RTW has also been found to be a facilitator for RTW after stroke from an employer perspective.[18] However, high ambitions in the RTW process could generate setbacks, as shown in this study. Disagreements with doctors, employers, or family members could be a concern when readiness for RTW is uncertain which has also previously been reported.[19] The importance of achieving appropriate, gradual RTW in combination with formal adjustments provided by the employer needs to be addressed, as previously suggested.[11]

Although having successfully RTW and still working 7-8 years after stroke, life was often restricted for participants in this study. Setting limits at work, omitting leisure- and social activities to meet an excessive need for rest, as well as trying to avoid work related stress were central strategies used to manage work life, in line with previous findings.[12] Consequently, this could mean prioritizing work and rest, having no spare energy for other life activities. On the other hand, having gained a more relaxed approach to work after stroke, some participants prioritized wellbeing and leisure activities and were content with a less senior work role or with working part-time when possible. The importance of work for wellbeing and life satisfaction after stroke has been emphasized.[14] We argue that maintaining work could be a continuous struggle many years after stroke and the use and success of coping strategies are dependent on each individual work situation, where the question of support from employers has a great impact on working conditions.

Some felt supported by their employer and others did not, maintaining work life at the expense of their own wellbeing, which could lead to the risk of future resignation, as previously presented.[12] Receiving no support from their employer could be related to difficulties in communicating impairments and adjustment needs, in particular when impairments were invisible. This could be a concern for managing work in the long run, as hidden impairments acting as key barriers for RTW has previously been suggested.[11] Employers' lack of medical knowledge, especially regarding cognitive impairments, could restrict them in making adequate adjustments.[13] Apart from gaining stroke specific knowledge from their employee, employers have used the internet as their primary source of information.[18] Thus, the communication of impairments and needs for adjustments to the employer seems crucial for receiving the support needed in the RTW process. To facilitate this communication, a stroke coordinator, who would support patients and stakeholders during the RTW process, has been suggested.[13, 20]

Clinical and policy implications

In this study, most participants had a mild stroke and were discharged from the hospital directly to their homes. Nevertheless, most still experienced cognitive impairments and fatigue that interfered with work life many years later. Cognitive impairments persisting for many years after stroke, also in people with mild stroke, have been presented previously.[21] Further, cognitive function has been found to predict RTW in people with mild to moderate stroke,[22] but cognitive rehabilitation interventions have focused little on this group.[22, 23] In relation to this and the findings of our study, we suggest that more attention should be given to rehabilitation of the invisible impairments experienced by people with mild to moderate stroke in the RTW process. However, a systematic review of RTW interventions found the evidence of effectiveness of cognitive rehabilitation by itself or in combination with work-directed interventions to be low.[24]

Based on the results of our study and previous findings, the strategies used to cope with invisible impairments in the RTW process after stroke seem to be essential.[11, 12] Development of strategies such as balancing activity and rest, setting limits, and avoiding work related stress could be supported by stroke rehabilitation teams. However, interventions for managing fatigue after stroke have insufficient evidence.[25]

It seems important to encourage patients to contact their workplace early in order to facilitate communication about their individual impairments and needs in the RTW process, to receive adjustments and social support from their employer. Rehabilitation meetings with the patient and involved stakeholders could be a forum for such information sharing. In line with our suggestion, there is strong evidence for the effect of interventions including a combination of work-directed components and education/coaching on RTW.[24]

Future research

Investigating aspects of work life many years after stroke, quantitative studies or studies using mixed methods to combine patient perspective with quantitative data on work stability, cognitive impairments, and fatigue would add generalizable knowledge.

Randomized controlled trials focusing on strategies to cope with, and communicate cognitive impairments and fatigue in the RTW process for persons with mild to moderate stroke are called for. Interventions could be based on strategies for managing work life after stroke as presented in this study.

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Author contribution

AP, MT, and KSS contributed to the design of the study. AP conducted and transcribed the interviews and analyzed the data together with MT, involving KSS in the final stages of analysis. AP and MT wrote the first version of the manuscript, which was reviewed by KSS. All three authors contributed to and approved the final manuscript.

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Competing interests

None declared.

REFERENCES

1 Young AE, Roessler RT, Wasiak R, et al. A developmental conceptualization of return to work. *Journal of occupational rehabilitation* 2005;15(4):557-68.
2 Riksstroke (the Swedish Stroke Resister). Yearly report (Acute-, TIA- and 3 month follow-up). 2015. Available from: www.riksstroke.org/wp-content/uploads/2015/12/Strokerapport_AKUT-TIA_LR.pdf.
3 Hannerz H, Holbaek Pedersen B, Poulsen OM, et al. A nationwide prospective cohort study on return to gainful occupation after stroke in Denmark 1996-2006. *BMJ Open* 2011;1(2):e000180.
4 Larsen LP, Biering K, Johnsen SP, et al. Self-rated health and return to work after first-time stroke. *J Rehabil Med* 2016;48(4):339-45.
5 Endo M, Sairenchi T, Kojimahara N, et al. Sickness absence and return to work among Japanese stroke survivors: a 365-day cohort study. *BMJ Open* 2016;6(1):e009682.
6 Glader EL, Jonsson B, Norrving B, et al. Socioeconomic factors' effect on return to work after first stroke. *Acta neurologica Scandinavica* 2017;135(6):608-13.
7 Westerlind E, Persson HC, Sunnerhagen KS. Return to Work after a Stroke in Working Age Persons; A Six-Year Follow Up. *PLoS One* 2017;12(1):e0169759.
8 Cancelliere C, Donovan J, Stochkendahl MJ, et al. Factors affecting return to work after injury or illness: best evidence synthesis of systematic reviews. *Chiropractic & manual therapies* 2016;24(1):32.
9 Wang YC, Kapellusch J, Garg A. Important factors influencing the return to work after stroke. *Work (Reading, Mass)* 2014;47(4):553-9.
10 Virtanen M, Ervasti J, Mittendorfer-Rutz E, et al. Work disability before and after a major cardiovascular event: a ten-year study using nationwide medical and insurance registers. *Scientific reports* 2017;7(1):1142.

11 Schwarz B, Claros-Salinas D, Streibelt M. Meta-Synthesis of Qualitative Research on Facilitators and Barriers of Return to Work After Stroke. *J Occup Rehabil* 2017.
12 Balasooriya-Smeekens C, Bateman A, Mant J, et al. Barriers and facilitators to staying in work after stroke: insight from an online forum. *BMJ Open* 2016;6(4):e009974.
13 Hellman T, Bergstrom A, Eriksson G, et al. Return to work after stroke: Important aspects shared and contrasted by five stakeholder groups. *Work (Reading, Mass)* 2016;55(4):901-11.
14 Vestling M, Tufvesson B, Iwarsson S. Indicators for return to work after stroke and the importance of work for subjective well-being and life satisfaction. *Journal of Rehabilitation Medicine* 2003;35(3):127-31.
15 Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative research in psychology* 2006;3(2):77-101.
16 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care : journal of the International Society for Quality in Health Care* 2007;19(6):349-57.
17 Christiansen CH. Defining lives: Occupation as identity: An essay on competence, coherence, and the creation of meaning. *American Journal of Occupational Therapy* 1999;53(6):547-58.
18 Coole C, Radford K, Grant M, et al. Returning to work after stroke: perspectives of employer stakeholders, a qualitative study. *J Occup Rehabil* 2013;23(3):406-18.
19 Gilworth G, Phil M, Cert A, et al. Personal experiences of returning to work following stroke: An exploratory study. *Work (Reading, Mass)* 2009;34(1):95-103.
20 Ost Nilsson A, Eriksson G, Johansson U, et al. Experiences of the return to work process after stroke while participating in a person-centred rehabilitation programme. *Scand J Occup Ther* 2017;24(5):349-56.
21 Ytterberg C, Dyback M, Bergstrom A, et al. Perceived impact of stroke six years after onset, and changes in impact between one and six years. *J Rehabil Med* 2017;49(8):637-43.
22 van der Kemp J, Kruithof WJ, Nijboer TC, et al. Return to work after mild-to-moderate stroke: work satisfaction and predictive factors. *Neuropsychological Rehabilitation* 2017:1-16.
23 Faux SG, Arora P, Shiner CT, et al. Rehabilitation and education are underutilized for mild stroke and TIA sufferers. *Disabil Rehabil* 2017:1-5.
24 Donker-Cools BH, Daams JG, Wind H, et al. Effective return-to-work interventions after acquired brain injury: A systematic review. *Brain Inj* 2016;30(2):113-31.
25 Hinkle JL, Becker KJ, Kim JS, et al. Poststroke Fatigue: Emerging Evidence and Approaches to Management: A Scientific Statement for Healthcare Professionals From the American Heart Association. *Stroke* 2017;48(7):e159-e70.

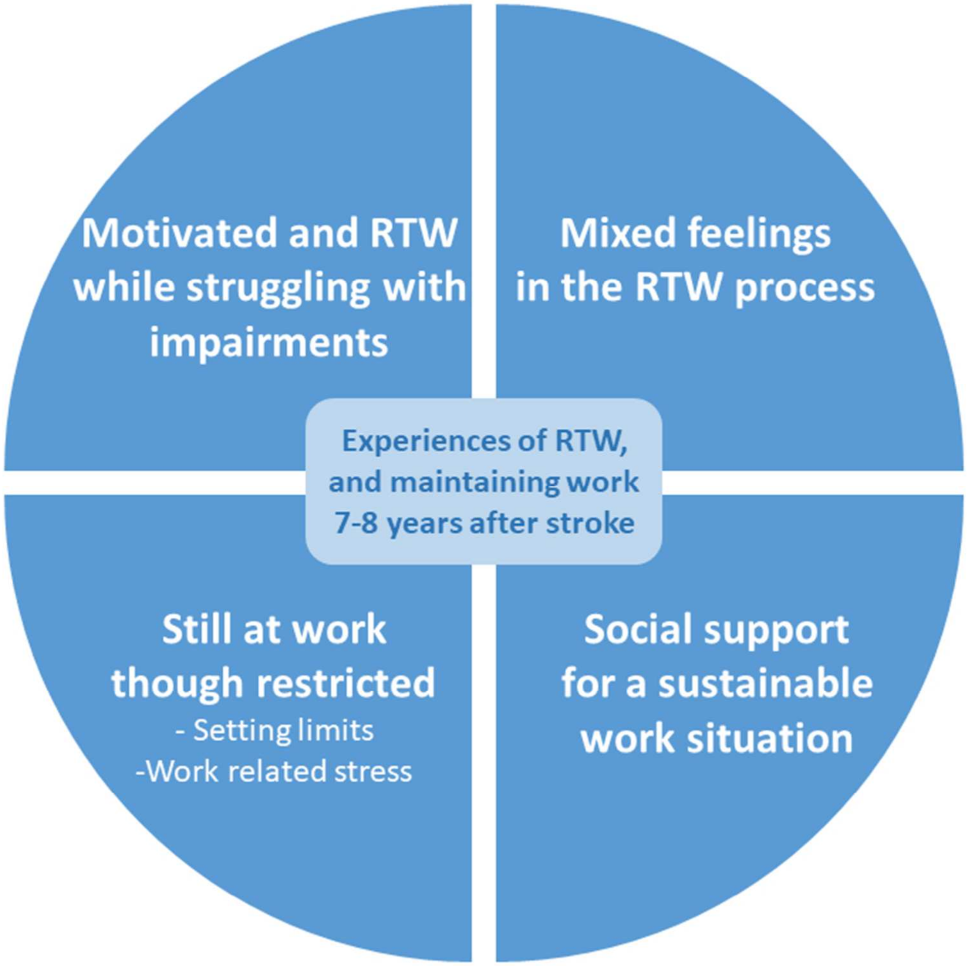

Fig 1. Themes and sub-themes developed in the analysis.

59x60mm (300 x 300 DPI)

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Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups

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Abstract

Background. Qualitative research explores complex phenomena encountered by clinicians, health care providers, policy makers and consumers. Although partial checklists are available, no consolidated reporting framework exists for any type of qualitative design.

Objective. To develop a checklist for explicit and comprehensive reporting of qualitative studies (indepth interviews and focus groups).

Methods. We performed a comprehensive search in Cochrane and Campbell Protocols, Medline, CINAHL, systematic reviews of qualitative studies, author or reviewer guidelines of major medical journals and reference lists of relevant publications for existing checklists used to assess qualitative studies. Seventy-six items from 22 checklists were compiled into a comprehensive list. All items were grouped into three domains: (i) research team and reflexivity, (ii) study design and (iii) data analysis and reporting. Duplicate items and those that were ambiguous, too broadly defined and impractical to assess were removed.

Results. Items most frequently included in the checklists related to sampling method, setting for data collection, method of data collection, respondent validation of findings, method of recording data, description of the derivation of themes and inclusion of supporting quotations. We grouped all items into three domains: (i) research team and reflexivity, (ii) study design and (iii) data analysis and reporting.

Conclusions. The criteria included in COREQ, a 32-item checklist, can help researchers to report important aspects of the research team, study methods, context of the study, findings, analysis and interpretations.

Keywords: focus groups, interviews, qualitative research, research design

Qualitative research explores complex phenomena encountered by clinicians, health care providers, policy makers and consumers in health care. Poorly designed studies and inadequate reporting can lead to inappropriate application of qualitative research in decision-making, health care, health policy and future research.

Formal reporting guidelines have been developed for randomized controlled trials (CONSORT) [1], diagnostic test studies (STARD), meta-analysis of RCTs (QUOROM) [2], observational studies (STROBE) [3] and meta-analyses of observational studies (MOOSE) [4]. These aim to improve the quality of reporting these study types and allow readers to better understand the design, conduct, analysis and findings of published studies. This process allows users of published research to be more fuller informed when they critically appraise studies relevant to each checklist and decide upon applicability of research findings to their local settings. Empiric studies have shown that the use of the CONSORT statement is associated with improvements in the quality of reports of randomized controlled trials [5]. Systematic reviews of qualitative research almost always show that key aspects of study design are not reported, and so there is a clear need for a CONSORT-equivalent for qualitative research [6].

The Uniform Requirements for Manuscripts Submitted to Biomedical Journals published by the International Committee of Medical Journal Editors (ICMJE) do not provide reporting guidelines for qualitative studies. Of all the mainstream biomedical journals (Fig. 1), only the British Medical Journal (BMJ) has criteria for reviewing qualitative research. However, the guidelines for authors specifically record that the checklist is not routinely used. In addition, the checklist is not comprehensive and does not provide specific guidance to assess some of the criteria. Although checklists for critical appraisal are available for qualitative research, there is no widely endorsed reporting framework for any type of qualitative research [7].

We have developed a formal reporting checklist for in-depth interviews and focus groups, the most common methods for data collection in qualitative health research.

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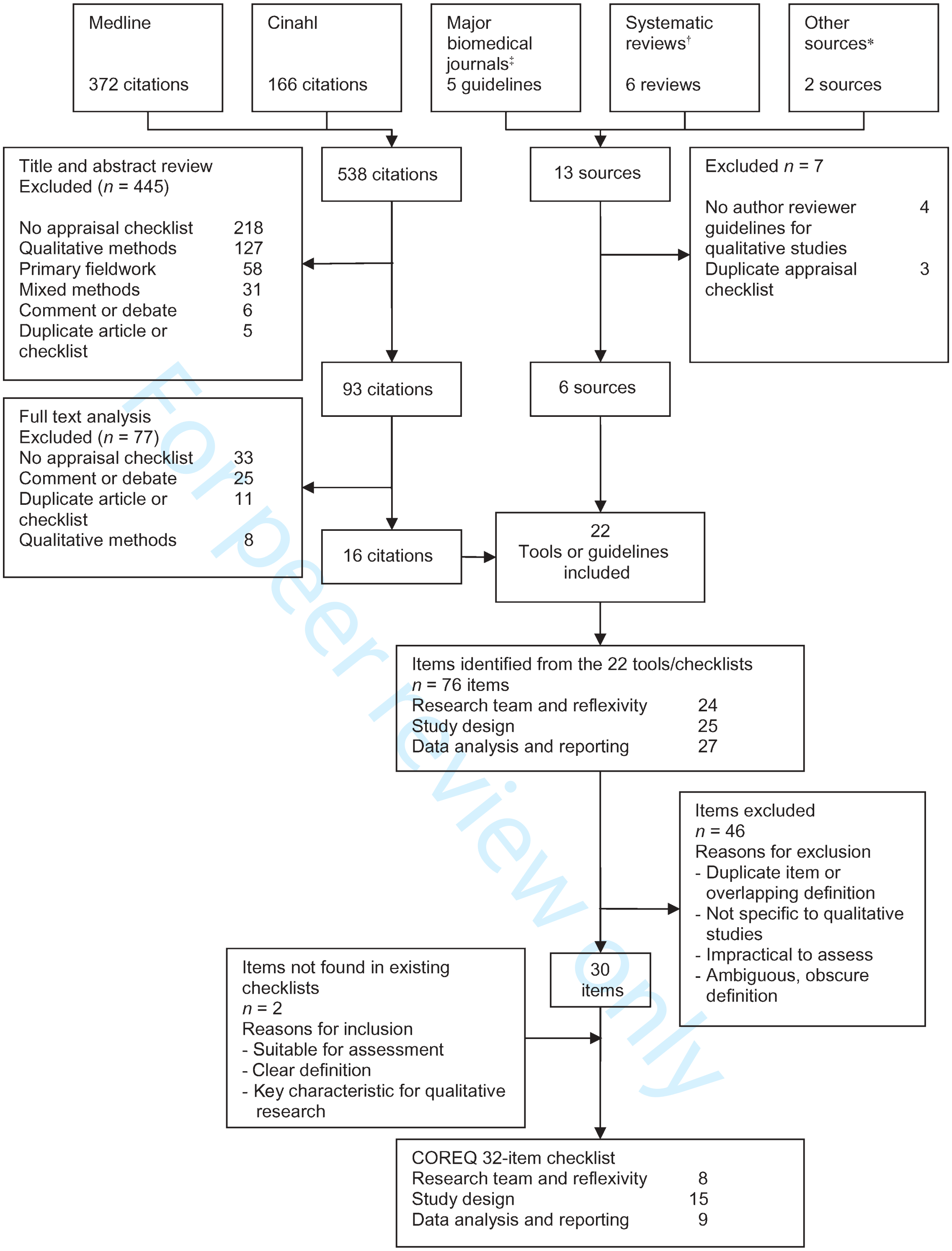

Figure 1 Development of the COREQ Checklist. *References [26, 27], †References [6, 28–32], ‡Author and reviewer guidelines provided by BMJ, JAMA, Lancet, Annals of Internal Medicine, NEJM.

These two methods are particularly useful for eliciting patient and consumer priorities and needs to improve the quality of health care [8]. The checklist aims to promote complete and transparent reporting among researchers and indirectly improve the rigor, comprehensiveness and credibility of interview and focus-group studies.

Basic definitions

Qualitative studies use non-quantitative methods to contribute new knowledge and to provide new perspectives in health care. Although qualitative research encompasses a broad range of study methods, most qualitative research publications in health care describe the use of interviews and focus groups [8].

Interviews

In-depth and semi-structured interviews explore the experiences of participants and the meanings they attribute to them. Researchers encourage participants to talk about issues pertinent to the research question by asking open-ended questions, usually in one-to-one interviews. The interviewer might re-word, re-order or clarify the questions to further investigate topics introduced by the respondent. In qualitative health research, in-depth interviews are often used to study the experiences and meanings of disease, and to explore personal and sensitive themes. They can also help to identify potentially modifiable factors for improving health care [9].

Focus groups

Focus groups are semi-structured discussions with groups of 4–12 people that aim to explore a specific set of issues [10]. Moderators often commence the focus group by asking broad questions about the topic of interest, before asking the focal questions. Although participants individually answer the facilitator's questions, they are encouraged to talk and interact with each other [11]. This technique is built on the notion that the group interaction encourages respondents to explore and clarify individual and shared perspectives [12]. Focus groups are used to explore views on health issues, programs, interventions and research.

Methods

Development of a checklist

Search strategy. We performed a comprehensive search for published checklists used to assess or review qualitative studies, and guidelines for reporting qualitative studies in: Medline (1966—Week 1 April 2006), CINAHL (1982—Week 3 April 2006), Cochrane and Campbell protocols, systematic reviews of qualitative studies, author or reviewer guidelines of major medical journals and reference lists of relevant publications. We identified the terms used to index the relevant articles already in our possession and performed a broad search using those search terms. The electronic databases were searched using terms and text words for research (standards), health services research (standards) and qualitative studies (evaluation). Duplicate checklists and detailed instructions for conducting and analysing qualitative studies were excluded.

Data extraction. From each of the included publications, we extracted all criteria for assessing or reporting qualitative studies. Seventy-six items from 22 checklists were compiled into a comprehensive list. We recorded the frequency of each item across all the publications. Items most frequently included in the checklists related to sampling method, setting for data collection, method of data collection, respondent validation of findings, method of recording data, description of the derivation of themes and inclusion of supporting quotations. We grouped all items into three domains: (i) research team and reflexivity, (ii) study design and (iii) data analysis and reporting. (see Tables 2–4)

Within each domain we simplified all relevant items by removing duplicates and those that were ambiguous, too broadly defined, not specific to qualitative research, or impractical to assess. Where necessary, the remaining items were rephrased for clarity. Based upon consensus among the authors, two new items that were considered relevant for reporting qualitative research were added. The two new items were identifying the authors who conducted the interview or focus group and reporting the presence of non-participants during the interview or focus group. The COREQ checklist for explicit and comprehensive reporting of qualitative studies consists of 32 criteria, with a descriptor to supplement each item (Table 1).

COREQ: content and rationale (see Tables 1)

Domain 1: research team and reflexivity

(i) Personal characteristics: Qualitative researchers closely engage with the research process and participants and are therefore unable to completely avoid personal bias. Instead researchers should recognize and clarify for readers their identity, credentials, occupation, gender, experience and training. Subsequently this improves the credibility of the findings by giving readers the ability to assess how these factors might have influenced the researchers' observations and interpretations [13–15].

(ii) Relationship with participants: The relationship and extent of interaction between the researcher and their participants should be described as it can have an effect on the participants' responses and also on the researchers' understanding of the phenomena [16]. For example, a clinician–researcher may have a deep understanding of patients' issues but their involvement in patient care may inhibit frank discussion with patient–participants when patients believe that their responses will affect their treatment. For transparency, the investigator should identify and state their assumptions and personal interests in the research topic.

Domain 2: study design

(i) Theoretical framework: Researchers should clarify the theoretical frameworks underpinning their study so readers can understand how the researchers explored their research questions and aims. Theoretical frameworks in qualitative research include: grounded theory, to build theories from the data; ethnography, to understand the culture of groups with shared characteristics; phenomenology, to describe the meaning and significance of experiences; discourse analysis, to analyse linguistic expression; and content analysis, to systematically organize data into a structured format [10].

Table 1 Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*
3.	Occupation	What was their occupation at the time of the study?
4.	Gender	Was the researcher male or female?
5.	Experience and training	What experience or training did the researcher have?
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement?
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*
Participant selection		
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*
12.	Sample size	How many participants were in the study?
13.	Non-participation	How many people refused to participate or dropped out? Reasons?
Setting		
14.	Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace*
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*
Data collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?
20.	Field notes	Were field notes made during and/or after the interview or focus group?
21.	Duration	What was the duration of the interviews or focus group?
22.	Data saturation	Was data saturation discussed?
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?
Domain 3: analysis and findingsz		
Data analysis		
24.	Number of data coders	How many data coders coded the data?
25.	Description of the coding tree	Did authors provide a description of the coding tree?
26.	Derivation of themes	Were themes identified in advance or derived from the data?
27.	Software	What software, if applicable, was used to manage the data?
28.	Participant checking	Did participants provide feedback on the findings?
Reporting		
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g. participant number*
30.	Data and findings consistent	Was there consistency between the data presented and the findings?
31.	Clarity of major themes	Were major themes clearly presented in the findings?
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?

(ii) Participant selection: Researchers should report how participants were selected. Usually purposive sampling is used which involves selecting participants who share particular characteristics and have the potential to provide rich, relevant and diverse data pertinent to the research question [13, 17]. Convenience sampling is less optimal because it may fail to capture important perspectives from difficult-to-reach people [16]. Rigorous attempts to recruit participants and reasons for non-participation should be stated to reduce the likelihood of making unsupported statements [18].

Table 2 Items included in 22 published checklists: Research team and reflexivity domain

Item	References																					
	[26][a]	[27][a]	[6][b]	[28][b]	[32][b]	[13]	[15]	[14]	[17]	[33]	[34]	[35]	[16]	[19]	[36]	[7]	[37]	[23]	[38]	[39]	[22]	BMJ
Research team and reflexivity																						
Nature of relationship between the researcher and participants		●		●	●		●		●						●				●			
Examination of role, bias, influence	●	●			●	●	●	●							●						●	
Description of role		●		●					●	●				●	●					●	●	
Identity of the interviewer		●		●		●					●		●		●							
Continued and prolonged engagement		●				●							●	●					●	●		
Response to events	●	●				●	●	●														
Prior assumptions and experience		●						●									●			●		
Professional status		●					●								●							
Journal, record of personal experience		●								●				●								
Effects of research on researcher		●				●	●															
Qualifications		●													●							
Training of the interviewer/facilitator			●		●																	
Expertise demonstrated		●																	●			
Perception of research at inception								●						●								
Age							●															
Gender							●															
Social class							●															
Reasons for conducting study		●																				
Sufficient contact													●									
Too close to participants													●									
Empathy																	●					
Distance between researcher and participants							●															
Background								●														
Familiarity with setting																					●	

[a]Other publications, [b]Systematic review of qualitative studies; BMJ, British Medical Journal—editor's checklist for appraising qualitative research); ●, item included in the checklist.

Table 3 Items included in 22 published checklists: Study design

Item	References																					
	[26][a]	[27][a]	[6][b]	[28] [b]	[32][b]	[13]	[15]	[14]	[17]	[33]	[34]	[35]	[16]	[19]	[36]	[7]	[37]	[23]	[38]	[39]	[22]	BMJ
Study design																						
Methodological orientation, ontological or epistemological basis		●		●				●	●					●					●	●	●	●
Sampling—convenience, purposive	●	●			●	●	●	●	●	●	●	●	●	●		●		●	●	●	●	●
Setting		●		●	●			●			●				●					●		
Characteristics and description of sample		●			●			●			●		●	●								
Reasons for participant selection	●	●				●		●			●											
Non-participation	●	●		●	●																	
Inclusion and exclusion, criteria		●			●	●													●			
Identity of the person responsible for recruitment				●	●						●				●							
Sample size		●		●	●						●										●	
Method of approach		●									●					●						
Description of explanation of research to participants	●				●										●							
Level and type of participation														●								
Method of data collection, e.g. focus group, in-depth interview	●	●	●	●	●	●		●	●		●	●	●	●		●				●	●	
Audio and visual recording	●	●	●	●	●	●				●	●		●						●		●	●
Transcripts			●	●	●	●			●		●		●						●			●
Setting and location	●	●		●	●		●		●		●				●						●	●
Saturation of data	●	●	●			●			●				●	●							●	
Use of a topic guide, tools, questions	●	●	●								●					●			●	●		
Field notes			●	●	●	●													●			●
Changes and modifications	●	●		●	●														●		●	
Duration of interview, focus group		●				●					●									●		
Sensitive to participant language and views		●										●		●								
Number of interviews, focus groups		●				●																
Time span																					●	
Time and resources available to the study		●																				

[a]Other publications, [b]Systematic review of qualitative studies; BMJ, British Medical Journal—editor's checklist for appraising qualitative research; ●, item included in the checklist.

Table 4 Items included in 22 published checklists: Analysis and reporting

Item	References																					
	[26][a]	[27][a]	[6][b]	[28][b]	[32][b]	[13]	[15]	[14]	[17]	[33]	[34]	[35]	[16]	[19]	[36]	[7]	[37]	[23]	[38]	[39]	[22]	BMJ
Respondent validation	●	●	●		●		●		●	●			●	●			●	●	●	●		
Limitations and generalizability	●	●		●	●		●		●		●		●	●				●	●			
Triangulation	●	●		●	●	●	●	●	●					●			●		●			
Original data, quotation		●	●	●	●			●	●		●			●		●				●	●	●
Derivation of themes explicit	●	●	●	●	●		●	●			●								●			●
Contradictory, diverse, negative cases	●	●		●	●		●			●				●					●			●
Number of data analysts	●	●	●			●			●			●	●						●			●
In-depth description of analysis	●			●	●			●			●			●							●	●
Sufficient supporting data presented	●	●		●	●		●				●					●						
Data, interpretation and conclusions linked and integrated		●		●	●							●		●						●		
Retain context of data		●					●	●						●					●			
Explicit findings, presented clearly	●	●		●					●	●												
Outside checks													●	●				●	●			
Software used		●				●													●			●
Discussion both for and against the researchers' arguments	●	●		●	●																	
Development of theories, explanations		●					●			●		●										
Numerical data		●									●							●				●
Coding tree or coding system		●					●												●		●	
Inter-observer reliability		●									●										●	
Sufficient insight into meaning/perceptions of participants		●								●												
Reasons for selection of data to support findings		●			●																	
New insight		●						●														
Results interpreted in credible, innovative way									●													
Eliminate other theories													●									
Range of views														●								
Distinguish between researcher and participant voices								●														
Proportion of data taken into account														●								

[a]Other publications, [b]Systematic review of qualitative studies; BMJ, British Medical Journal—editor's checklist for appraising qualitative research, ●, item included in the checklist.

Researchers should report the sample size of their study to enable readers to assess the diversity of perspectives included.

(iii) Setting: Researchers should describe the context in which the data were collected because it illuminates why participants responded in a particular way. For instance, participants might be more reserved and feel disempowered talking in a hospital setting. The presence of non-participants during interviews or focus groups should be reported as this can also affect the opinions expressed by participants. For example, parent interviewees might be reluctant to talk on sensitive topics if their children are present. Participant characteristics, such as basic demographic data, should be reported so readers can consider the relevance of the findings and interpretations to their own situation. This also allows readers to assess whether perspectives from different groups were explored and compared, such as patients and health care providers [13, 19].

(iv) Data collection: The questions and prompts used in data collection should be provided to enhance the readers' understanding of the researcher's focus and to give readers the ability to assess whether participants were encouraged to openly convey their viewpoints. Researchers should also report whether repeat interviews were conducted as this can influence the rapport developed between the researcher and participants and affect the richness of data obtained. The method of recording the participants' words should be reported. Generally, audio recording and transcription more accurately reflect the participants' views than contemporaneous researcher notes, more so if participants checked their own transcript for accuracy [19–21]. Reasons for not audio recording should be provided. In addition, field notes maintain contextual details and non-verbal expressions for data analysis and interpretation [19, 22]. Duration of the interview or focus group should be reported as this affects the amount of data obtained. Researchers should also clarify whether participants were recruited until no new relevant knowledge was being obtained from new participants (data saturation) [23, 24].

Domain 3: analysis and findings

(i) Data analysis: Specifying the use of multiple coders or other methods of researcher triangulation can indicate a broader and more complex understanding of the phenomenon. The credibility of the findings can be assessed if the process of coding (selecting significant sections from participant statements), and the derivation and identification of themes are made explicit. Descriptions of coding and memoing demonstrate how the researchers perceived, examined and developed their understanding of the data [17, 19]. Researchers sometimes use software packages to assist with storage, searching and coding of qualitative data. In addition, obtaining feedback from participants on the research findings adds validity to the researcher's interpretations by ensuring that the participants' own meanings and perspectives are represented and not curtailed by the researchers' own agenda and knowledge [23].

(ii) Reporting: If supporting quotations are provided, researchers should include quotations from different participants to add transparency and trustworthiness to their findings and interpretations of the data [17]. Readers should be able to assess the consistency between the data presented and the study findings, including the both major and minor themes. Summary findings, interpretations and theories generated should be clearly presented in qualitative research publications.

Discussion

The COREQ checklist was developed to promote explicit and comprehensive reporting of qualitative studies (interviews and focus groups). The checklist consists of items specific to reporting qualitative studies and precludes generic criteria that are applicable to all types of research reports. COREQ is a comprehensive checklist that covers necessary components of study design, which should be reported. The criteria included in the checklist can help researchers to report important aspects of the research team, study methods, context of the study, findings, analysis and interpretations.

At present, we acknowledge there is no empiric basis that shows that the introduction of COREQ will improve the quality of reporting of qualitative research. However this is no different than when CONSORT, QUOROM and other reporting checklists were introduced. Subsequent research has shown that these checklists have improved the quality of reporting of study types relevant to each checklist [5, 25], and we believe that the effect of COREQ is likely to be similar. Despite differences in the objectives and methods of quantitative and qualitative methods, the underlying aim of transparency in research methods and, at the least, the theoretical possibility of the reader being able to duplicate the study methods should be the aims of both methodological approaches. There is a perception among research funding agencies, clinicians and policy makers, that qualitative research is 'second class' research. Initiatives like COREQ are designed to encourage improvement in the quality of reporting of qualitative studies, which will indirectly lead to improved conduct, and greater recognition of qualitative research as inherently equal scientific endeavor compared with quantitative research that is used to assess the quality and safety of health care. We invite readers to comment on COREQ to improve the checklist.

References

1. Moher D, Schulz KF, Altman D. The CONSORT statement: revised recommendations for improving the quality of reports of parallel-group randomized trials. *JAMA* 2001;**285**:1987–91.
2. Moher D, Cook DJ, Eastwood S *et al.* Improving the quality of reports of meta-analyses of randomised controlled trials: the QUOROM statement. Quality of Reporting of Meta-analyses. *Lancet* 1999;**354**:1896–900.

3. STROBE Statement: Strengthening the reporting of observational studies in epidemiology. http://www.strobe-statement.org/Checkliste.html
4. Stroup DF, Berlin JA, Morton SC *et al.* Meta-analysis of observational studies in epidemiology: a proposal for reporting. Meta-analysis Of Observational Studies in Epidemiology (MOOSE) group. *JAMA* 2000;**283**:2008–12.
5. Moher D, Jones A, Lepage L. Use of the CONSORT Statement and quality of reports of randomized trials. A comparative before-and-after evaluation. *JAMA* 2001;**285**:1992–5.
6. Mills E, Jadad AR, Ross C *et al.* Systematic review of qualitative studies exploring parental beliefs and attitudes toward childhood vaccination identified common barriers to vaccination. *J Clin Epidemiol* 2005;**58**:1081–8.
7. Knafl KA, Howard NJ. Interpreting and reporting qualitative research. *Res Nurs Health* 1984;**7**:7–14.
8. Sofaer S. Qualitative research methods. *Int J Qual Health Care* 2002;**14**:329–36.
9. Wright EB, Holcombe C, Salmon P. Doctor's communication of trust, care, and respect in breast cancer: qualitative study. *BMJ* 2004;**328**:864–8.
10. Liamputtong P, Ezzy D. *Qualitative Research Methods*. 2nd edn. Melbourne, Victoria: Oxford University Press, 2005.
11. Krueger RA, Casey MA. *Focus Groups. A Practical Guide for Applied Research*. Thousand Oaks CA: Sage Publications, 2000.
12. Morgan DL. *Focus Groups as Qualitative Research*. Newbury Park, California: Sage, 1988.
13. Giacomini MK, Cook DJ. Users' guides to the medical literature XXIII. Qualitative research in health care. A. Are the results of the study valid? *JAMA* 2000;**284**:357–62.
14. Malterud K. Qualitative research:standards challenges guidelines. *Lancet* 2001;**358**:483–8.
15. Mays N, Pope C. Qualitative research in health care: assessing quality in qualitative research. *BMJ* 2000;**320**:50–2.
16. Elder NC, William L. Reading and evaluating qualitative research studies. *J Fam Pract* 1995;**41**:279–85.
17. Cote L, Turgeon J. Appraising qualitative research articles in medicine and medical education. *Med Teach* 2005;**27**:71–5.
18. Altheide D, Johnson J. Criteria for assessing interpretive validity in qualitative research. In Denzin N, Lincoln Y (eds). *Handbook of Qualitative Research*. Thousand Oaks CA: Sage Publications, 1994.
19. Fossey E, Harvey C, McDermott F *et al.* Understanding and evaluating qualitative research. *Aust N Z J Psychiatry* 2002;**36**:717–32.
20. Seale C, Silverman S. Ensuring rigour in qualitative research. *Eur J Public Health* 1997;**7**:379–84.
21. Scheff T. Single case analysis in the health sciences. *Eur J Public Health* 1995;**5**:72–4.
22. Bluff R. Evaluating qualitative research. *Br J Midwifery* 1997;**5**:232–5.
23. Popay J, Rogers A, Williams G. Rationale and standards for the systematic review of qualitative literature in health services research. *Qual Health Res* 1998;**8**:341–51.
24. Blumer H. *Critiques of Research, in the Social Sciences*. New Brunswick, NJ: Transaction Books, 1979.
25. Delaney A, Bagshaw SM, Ferland A *et al.* A systematic evaluation of the quality of meta-anlyses in the critical care literature. *Crit Care* 2005;**9**:575–82.
26. Critical Skills Appraisal Programme (CASP) 10 Questions to help you make sense of qualitative research: Milton Keynes Primary Care Trust, 2002.
27. Spencer L, Ritchie J, Lewis J *et al. Quality in Qualitative Evaluation: A Framework for Assessing Research Evidence.* London: Cabinet Office. Government Chief Social Researcher's Office, 2003.
28. Campbell R, Pound P, Pope C *et al.* Evaluating meta-ethnography: a synthesis of qualitative research on lay experience of diabetes and diabetes care. *Soc Sci Med* 2003;**56**:671–84.
29. Feder GS, Hutson M, Ramsay I *et al.* Women exposed to intimate partner violence: expectations and experiences when they encounter health care professionals: a meta-analysis of qualitative studies. *Arch Intern Med* 2006;**166**:22–37.
30. Pound P, Britten N, Morgan M *et al.* Resisting medicines: a synthesis of qualitative studies of medicine taking. *Soc Sci Med* 2005;**61**:133–55.
31. Smith LK, Pope C, Botha JL. Patients' help-seeking experiences and delay in cancer presentation: a qualitative synthesis. *Lancet* 2005;**366**:825–31.
32. Walter FM, Emery J, Braithwaite D *et al.* Lay understanding of familial risk of common chronic diseases: a systematic review and synthesis of qualitative research. *Ann Fam Med* 2004;**2**:583–94.
33. Inui TS, Frankel RM. Evaluating the quality of qualitative research: a proposal pro-term. *J Gen Intern Med* 1991;**6**:485–6.
34. Boulton M, Fitzpatrick R, Swinburn C. Qualitative research in health care: II A structured review and evaluation of studies. *J Eval Clin Pract* 1996;**2**:171–9.
35. Dixon-Woods M, Shaw RL, Agarwal S *et al.* The problem of appraising qualitative research. *Qual Saf Health Care* 2004;**13**:223–5.
36. Hoddinott P, Pill R. A review of recently published qualitative research in general practice. More methodological questions than answers? *Fam Pract* 1997;**14**:313–9.
37. Kuzel AJ, Engel JD, Addison RB *et al.* Desirable features of qualitative research. *Fam Pract Res J* 1994;**14**:369–78.
38. Treloar C, Champness S, Simpson PL *et al.* Critical appraisal checklist for qualitative research studies. *Indian J Pediatr* 2000;**67**:347–51.
39. Cesario S, Morin K, Santa-Donato A. Evaluating the level of evidence in qualitative research. *J Obstet Gynecol Neonatal Nurs* 2001;**31**:708–14.

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COREQ 32-item checklist for interviews with page indications:

1. Interviewer: Page 7
2. Credentials: Page 7
3. Occupation: Page 7
4. Gender: Page 7
5. Experience and training: Page 7
6. Relationship established: Page 5
7. Participant knowledge of the interviewer: Page 5
8. Interviewer Characteristics: Page 5
9. Methodological orientation and theory: Page 7
10. Sampling: Page 5
11. Method of approach: Page 5
12. Sample size: Page 5
13. Non-participation: Page 5
14. Setting of data collection: Page 7
15. Presence of non-participants: Page 7
16. Description of sample: Page 5-6
17. Interview guide: Page 7
18. Repeat interviews: n.a.
19. Audio/visual recording: Page 7
20. Field notes: Page 7
21. Duration: Page 7
22. Data saturation: Page 7
23. Transcripts returned: Page 7
24. Number of data coders: Page 7
25. Description of the coding tree: Page 7
26. Derivation of themes: Page 7
27. Software: n.a.
28. Participant checking: Page 7
29. Quotations presented: Page 10-13
30. Data and findings consistent: Page 10-13
31. Clarity of major themes: Page 7 (Fig 1), page 10-13
32. Clarity of minor themes: Page 7 (Fig 1), page 10-13

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Experiences of returning to work, and maintaining work 7 to 8 years after stroke in Sweden - a qualitative interview study

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Experiences of returning to work, and maintaining work 7 to 8 years after stroke in Sweden - a qualitative interview study

ABSTRACT

Objective: To explore how persons experienced return to work and their work situation 7 to 8 years after stroke.

Design: The study had an explorative qualitative design with individual interviews. The data analysis was inductive thematic and two researchers cooperated during the analysis process.

Participants: The study population included five women and eight men who had a stroke during 2009-2010, received care at the Sahlgrenska University Hospital in Gothenburg, Sweden, and returned to work after stroke, a heterogenic sample based on age, occupation, stroke severity, and time to return to work.

Results: The analysis led to four themes revealing that participants were motivated to RTW while struggling with impairments in the RTW process. The RTW process evoked mixed feelings of worry and grief over lost functions but also acceptance and gratitude for being able to work. Although maintaining work 7 to 8 years after stroke, most were restricted in some way. Fatigue and cognitive impairments meant having to set limits, omit work tasks, and rest at work, but also rest during free time and omit social activities in order to manage work life. Participants avoided work related stress if they could because of aggravated symptoms and/or fear of a new stroke. Support from supervisors and colleagues was often crucial for a sustainable work situation but when not supported or even discouraged at work, it could mean a lonesome struggle to endure impairments and stress related symptoms while pushing their limits to manage work demands.

Conclusion Maintaining work can be a continuous struggle with invisible impairments many years after stroke. Strategies for managing work are dependent on each individual work situation, where support and understanding at work seem to be crucial for a sustainable work situation.

Strengths and limitations of this study (bullet points)

- The focus of this study was the perspective of persons who had worked for years since their stroke, but apart from having this in common, they represented a wide range of occupations, stroke characteristics, and social backgrounds, gave rich interviews and contributed with experiences of maintaining work life after stroke.
- The patient perspective was integrated throughout the study as the interview guide was developed in cooperation with a patient representative from the Swedish Stroke

Association, with whom a pilot interview was conducted, and further in the analysis process the participants were invited to a meeting to discuss and give feedback on the results (participant checking), which gave credibility to the interpretations.

- A limitation of this study was that it only considered the perspective of persons who had RTW after stroke, and not included other stakeholders in the RTW process.
- This study was performed in the Swedish context and the transferability of results to other cultural contexts needs consideration.

INTRODUCTION

Return to work (RTW) is commonly referred to as the event when resuming work after a period of sick leave although a broader view has been suggested to include the whole RTW process, from initial work disability to reaching ones' full potential at work.[1] In Sweden, 25-30 000 people suffer a stroke each year, of whom 20% are of working age, an age group in which stroke has become more common in recent years.[2] The reported RTW rate between one to three years after stroke varies globally between 50 to 74 percent,[3-7] of which two Swedish studies found a RTW rate of 74%.[6, 7] In Sweden, employers have the most explicit responsibility of rehabilitation concerning their employees´ RTW, although shared with health care, the Social Insurance Office (SIO) and the Employment Agency (EA). Employers are obliged to adapt work tasks, working hours, start work trials, and make technical adjustments, though they are not forced to expand or create new work tasks. Common predictors for RTW in people with non-communicable diseases have been found to be higher socioeconomic status, higher self-efficacy, and positive expectations of recovery, less severe illness, better RTW coordination, and multidisciplinary interventions including the workplace.[8] For stroke, less sever stroke and good self-rated health have been reported to be predictors for RTW.[4] Predictors for no RTW have been reported to be physical dependency at discharge,[7] degree of residual disability,[9] sick leave-,[7] or unemployment,[10] prior to stroke, low socioeconomic status,[6] being an immigrant,[10] comorbidities,[10] older age,[5] and being female.[3]

A recent meta-synthesis of qualitative studies on RTW after stroke summarized important factors relative to RTW such as those related to rehabilitation services (availability, accessibility, and appropriateness), the person (impairments, coping, adaptation, and motivation), and the workplace (demands, adaptations, disability management, work climate, and social support).[11] Another qualitative study found that awareness of invisible impairments generated support from employers and colleagues at work and a positive work experience, whereas the opposite presented a large barrier for RTW.[12] A qualitative study suggested the importance of a coordinator for communicating information between stakeholders in the RTW process.[13] Work has been found to be of importance for well-being and life satisfaction after stroke,[14] and RTW can be seen as a strive for normality.[12] Although many studies have investigated factors influencing return or no return to work after stroke, few have studied experiences of working in the long run after stroke.

The aim of this study was to explore experiences of returning to work and maintaining work seven to eight years after stroke.

METHODS

Study design

This is an explorative qualitative study using individual interviews and inductive thematic analysis.[15] The COREQ guidelines for reporting qualitative research were used.[16] The study was approved by the Regional Ethics Committee in Gothenburg, Sweden, on June 5th 2013 (Dnr: 400-13). Oral and written information was given and written informed consent was received.

Patient and Public involvement

The research question was developed with the aim of learning more about the experiences of persons who had returned to work after having had a stroke. A patient representative from the Swedish Stroke Association was involved in the development and pilot testing of the interview guide. Patients were involved in the conduct of the study, in individual interviews and when invited to a meeting to hear the results and to discuss the interpretation with the authors. The preliminary results of the analysis have been delivered to the study participants in a written letter.

Participants

Participants were identified in the Extended Stroke Arm Longitudinal study at the University of Gothenburg, SALGOT-extended. The inclusion criteria were; having suffered an ischemic or hemorrhagic stroke in the years 2009-2010, having received care at the Sahlgrenska University Hospital in Gothenburg, Sweden, residing in the Gothenburg urban area, being of working age (18-64), and having RTW after stroke. Eighty-two persons were potentially eligible and a letter including information about the purpose of the study, brief information about the clinical and research experience of the interviewer (AP) and information about the research team, was sent out to a purposive sample of 37 persons to achieve a heterogeneous study population based on age, gender, occupation, stroke severity (NIH Stroke Scale), and time to RTW. The letter was followed up by a telephone call by AP to confirm participation and to schedule interviews. If a person was not reached by telephone, another letter was sent out encouraging the person to make contact if they were interested in participating. Fourteen persons agreed to participate, but one was excluded due to not having RTW after stroke. The participants were asked to complete a form about demographics and employment. This is presented in Table 1 together with data retrieved from medical charts.

Table 1. Demographic and clinical characteristics of the study population

	Study population (n=13)
Age, mean years (min-max)	50 (39-64)

Gender: Female/Male	 5/8
Country of birth: Sweden Middle East or African country	 10 3
Current living conditions: Living alone Living with partner/ -and children	 5 3/5
Type of stroke: Ischemic stroke Intracerebral hemorrhage	 9 4
Stroke severity (NIH Stroke Scale): Mild Moderate Severe	 10 2 1
Stroke localization: Right hemisphere Left hemisphere Bilateral Not specified	 4 3 1 5
Discharged from stroke unit: Discharged home/ to rehab center	 9/4
Education: ≤ 9 years 10-12 years > 12 years	 5 3 5
Occupations:	Accountant Assistant nurse Civil Engineer Cleaner (n=2) Commander on ferry Dentist Economist Police inspector Production worker Service technician Terminal worker Vehicle fitter
Work related characteristics:	
Time to RTW (period of full time sick leave)	Range: 2 months – 2 years
Same employer as before stroke Lost job before RTW Lost job after RTW	11 1 1

Percent of employment at the time of the interview: 100% 75% 50%	 10 2 1
Employment: Employed in public sector Employed in private sector Self-employed Employed in sheltered work	 5 5 1 2

Data collection

Individual, face-to-face interviews were conducted by the first author (AP) who has a PhD, is a registered physiotherapist, has previous experience in performing qualitative studies, with no previous relation to the participants, and is a woman. A semi-structured interview guide with open-ended questions was used and is presented in Figure 1.The interview guide was discussed and revised in cooperation with a patient representative from the Swedish Stroke Association with whom it was first tested in a pilot interview. Thirteen interviews were performed during April to September 2017, three took place in the participants' homes and ten at the rehabilitation medicine research unit facilities. By request of one participant, the interview was conducted in the presence of a next of kin who clarified answers due to language difficulties. The duration of interviews ranged from 40 to 90 minutes. All interviews were audio-recorded and transcribed verbatim by the first author (AP). After 13 interviews, no new relevant knowledge was being obtained from new participants and hence, data saturation was considered to be achieved.[16]

Insert figure 1 about here

Data analysis

The transcribed interviews were analyzed by inductive thematic analysis[15] as described in Table 2.

Table 2. The steps of thematic analysis according to Braun and Clarke.

Steps	Description
1	Familiarization with data: transcribing, reading, re-reading, noting down initial ideas
2	Generating initial codes: coding interesting features across the entire data set
3	Searching for themes: collecting codes into potential themes, gathering all data relevant to each potential theme

4	Reviewing themes: checking if the themes work in relation to the coded extracts and the entire data set, generating a thematic map of the analysis.
5	Defining and naming themes: ongoing analysis to refine the specifics of each theme
6	Producing the report: the final opportunity for analysis, selection of vivid, compelling extract examples, relating back of the analysis to the research question and literature, producing a report of the analysis

First, the transcribed interviews were read and re-read by two of the authors (AP and MT). MT has a PhD and more than 30 years of experience as a social worker and with qualitative research methodology. The interviews were read separately by the two authors to familiarize with the text and to obtain a sense of the whole. In this process, initial codes were noted separately by the two authors. Second, the authors coded the interviews together and searched for potential themes. The themes were then reviewed and refined by all three authors together and differences were discussed until consensus was reached, with the aim of enhancing the credibility of the analysis. The third author (KSS) is a MD, stroke specialist and Professor in Rehabilitation Medicine with more than 25 years of clinical and research experience in neurological diagnoses. KSS contributed with stroke specific knowledge in discussions concerning revising and refining the themes. The analysis process moved continuously back and forth between the whole and parts of the text to ensure the validity of the themes in relation to the data set. The study participants were invited to a meeting to hear the results and to discuss the interpretation with the authors. Examples of the coding process are provided in Table 3.

Table 3. Examples illustrating the coding tree

Data extract	Code	Theme
(my boss says) "I see that you are tired, you need to rest. You need a break. Sit down there in the corner in my recliner and rest, I can see it in your eyes that you need a break, so I'm 'shutting you down' (like a machine) a little and I'll keep working."	Acknowledging symptoms and encouraging rest at work	Social support for a sustainable work situation
"they warned me that I'd be fatigued and stuff like that, but I thought I could handle it quite well with the gradual steps that I took. And there were planned rest days… And then the doctor said: people manage to start working pretty well, but it's important that you have longer recovery times, that are not broken up."	Experience of RTW at just the right pace	Motivated and returned to work while struggling with impairments

RESULTS

Four themes were identified; *motivated and RTW while struggling with impairments*, *mixed feelings in the RTW process*, *still at work though restricted* which includes two sub-themes, and *social support for a sustainable work situation* (Fig 2). The themes are illustrated with quotes from the participants.

Insert figure 2 about here

Motivated and returned to work while struggling with impairments

Participants described a wide range of impairments that initially affected RTW (Table 4).

Full time sick leave was prescribed for all participants and lasted from two months up to two years. Motivational factors for returning to work were an urge to leave the role of sick person behind, regaining a meaningful daily activity, strong work morals and work identity, economic needs, and a strive for normality.

" The best rehabilitation for me has been starting to work again and getting away from the being sick part, and I wanted to get out and, like, meet people…. It was a way to start to function normally again." Man, 39 years

All participants returned to work gradually in an individually adjusted pace and all but one returned to their previous job, who found a new full-time job. The RTW was sometimes too early or the gradual escalation was sometimes too rapid. This was related to high ambitions in combination with impairments and resulted in setbacks, such as fatigue and emotional stress, which forced a backwards step in the RTW process. This was frustrating, but manageable when focusing on striving forwards in the RTW process. Experiences of RTW at just the right pace or later than appropriate were also reported. They were hindered by doctors, work supervisors, or family members, raising feelings of disappointment or discouragement, but also feelings of being cared for.

"they warned me that I'd be fatigued and stuff like that, but I thought I could handle it quite well with the gradual steps that I took. And there were planned rest days… And then the doctor said: people manage to start working pretty well, but it's important that you have longer recovery times, that are not broken up." Man, 58 years

In the RTW process, individual adaptations of work time, work tasks, and the work environment were performed in partnership with the employer.

"He (my boss) has given me a good room and good nurses and good support, so like, a lot of stuff around me, he has been up for making sure I have calm surroundings and a stable room and not need to change between a bunch of different nurses, I have the same ones, so he's been very supportive in that way…" Woman, 57 years

Work demands were adjusted by refraining from works tasks and responsibilities. Some described no need for adaptations and were content with their work demands.

Table 4. Impairments affecting work initially in the RTW process and 7-8 years after stroke, as expressed by participants.

Initial impairments	**Residual impairments**
Altered mental functions	
Disorientation in time	
Disorientation in space	
Lack of initiative	
Difficulties concentrating	Difficulties concentrating
Difficulties multitasking	Difficulties multitasking
Difficulties processing information and impressions	Difficulties processing information and impressions
Difficulties with numbers and letters	
Memory difficulties	
Depression	
Fatigue	Fatigue
Altered sensory functions and pain	
Sensitivity to sound	
Sensory loss and alterations	
Headache	Headache
Balance difficulties	Vertigo and balance difficulties
Altered neuromusculoskeletal functions	
Muscle weakness on one side of the body	Muscle weakness on one side of the body
Coordination difficulties	
Altered voice and speech functions	
Losing volume of voice	

Mixed feelings in the RTW process

Uncertainty about consequences of stroke and prognosis of recovery raised worries about the future, including work life. Speculations about whether impairments were age- or stroke-related were expressed. Expectations of a fast recovery sometimes led to disappointment later when still struggling with impairments, or to satisfaction when the recovery rate turned out as expected. Some had been told by doctors that they would fully recover but when still struggling with impairments and work tasks 7-8 years after stroke they wondered how and when that would happen. However, gratitude for functioning well despite stroke when considering how life might have turned out was expressed; they had been given a second chance in life and could work.

"I'm happy to be able to work 75%, because I had a large stroke, so the idea that I'm able to work at all, that's completely amazing." Woman, 57 years

Acceptance of impaired functions as well as a more relaxed attitude towards work life were expressed. Participants described satisfaction with regained functions, but also frustration and grief over lost functions and disappointment at having been deprived of career opportunities.

Still at work though restricted

Seven to eight years after stroke, impairments were less obvious than initially post stroke, though most participants had impairments that still interfered with work (Table 4).

Setting limits

Setting limits for colleagues, patients, and customers to create opportunities for rest and undisturbed work was one strategy used to manage work demands. It was hard, and time consuming to shift focus and get back on track with their own work tasks after being disrupted by others, forcing participants to set limits for interaction with colleagues in order to focus on their own tasks. Limiting ambition was a way to avoid fatigue, this could mean delegating work tasks or accepting a more subordinate work role. When demands on multitasking and information processing were too high, this could lead to confusion, insecurity, and refraining from work tasks. Difficulties setting limits at work were experienced when expressed needs were not heard by supervisors or colleagues. Sometimes, participants chose not to participate in social activities at work due to fatigue, forced to focus on work tasks and nothing else.

"Some days are a lot, and you get interrupted the whole time during your breaks and stuff…though I try and work around that by not going on break when everyone else does. Sometimes I've thought that my brain needs to rest a little, it's fun to sit and chat with the others so I'm part of the group, but some days I feel… I want to take the opportunity to have a break when the others have gone so I can have a little bit of peace." Woman, 48 years

When trying to keep up appearances to compete with colleagues, one participant avoided setting limits. However, some found it easier to set limits now than before their stroke, they mentioned being able to stand up for themselves and knowing more about their rights.

Independent work was described to allow for work at their own pace, providing opportunities to prepare and plan work according to their own functional level. Fatigue was described as a dominant impairment that was coped with by taking pauses at work, which was allowed for at some workplaces but not at others.

“then there’s the fatigue, if I’m going to have a more complicated meeting with a customer, or if I need to have a wage renegotiation meeting or performance review, I always have them in the morning. I always plan them for the mornings, because in the afternoon I get more fatigued, unfortunately.” Woman, 45 years

Gaining insight post stroke into the importance of taking care of their own health sometimes led to prioritizing physical exercise in order to be able to function better at work. But finding the energy for exercise was sometimes impossible when they were stuck in the vicious circle of fatigue and work demands. Some described exercising less than before the stroke, due to the fear of a new stroke. Participants described an excessive need for rest, before and after work. Spare time activities were often neglected due to lack of energy and were replaced by rest and sleep to manage work.

“Before I had my stroke I had an allotment, so when I was finished at work I’d go and dig and do some work there. I rode my bike there. Now I just can’t manage it… I feel that things are different to before, but I want to live like that, like, I don’t want to push the limits, I want to try and live the way I am able to.” Man, 59 years

Work related stress

Work demands of being constantly available to customers, patients, or colleagues and a competitive work environment, lack of control of workload, and irregular inflow of work created stress. Also, having to adjust to changing work schedules, being forced to work overtime, or having to manage the same work demands as before stroke were stressful.

When exposed to stress at work, participants described having symptoms like the ones they had at stroke onset, such as sensations of numbness, tingling, and headache, which gave rise to the fear of having a new stroke.

“So every time you get a headache you start to think negatively, think if it’s another thing like that that is happening (a new stroke) … before I had the stroke, you could say I was very stressed out. But

now I don't stress as much. I think, nah it will take the time it takes and not stress too much, it's just that way. So, like at work right now, you work but not as intensively as you did before, and you have to think about your own health too." Man, 46 years

The participants tried to avoid work related stress but when this proved impossible, one started his own business to regain control over his workload. Others were forced to stress at work and endured recurrent symptoms such as headache, fatigue, vertigo, or high blood pressure and felt trapped because of economic needs or were too exhausted to change jobs.

Social support for a sustainable work situation

Participants felt looked after and privileged when supported by their supervisor. A supervisor could advocate work task adaptations, acknowledge symptoms, and encourage rest at work, or could accept flexible working hours.

(my boss says) "I see that you are tired, you need to rest. You need a break. Sit down there in the corner in my recliner and rest, I can see it in your eyes that you need a break, so I'm 'shutting you down' (like a machine) a little and I'll keep working." Woman, 48 years

Some participants did not feel supported by their supervisor, who ignored them and their needs which created a strenuous work situation. One supervisor gave mixed signals, both being supportive and setting unreasonable demands at the same time. One participant had been discouraged by the supervisor at a rehabilitation meeting but stood up against the supervisor and gained support that way. One participant felt actively discouraged by the supervisor and experienced that the supervisor tried to force them to resign.

"And she, my boss, doesn't accept the doctor's certificate but it's, I don't know what to say, they're against me…In two weeks I'm going to work nights, but I…they want me to take the week off unpaid. Last time it was a late shift I took holiday leave…" Man, 59 years

Participants said that it felt safe to return to the same work team, they got along well with colleagues when they could communicate openly and joke about their symptoms at work. When impairments did not interfere with work, some appreciated being treated like anyone else, but when impairments affected work, some appreciated to be relieved of work tasks, and receive social support from colleagues.

Societal support could mean assistance from a labor union, the Swedish Social Insurance Agency, or the Employment Agency in the RTW process. One could feel supported but also exposed by contact with these authorities.

DISCUSSION

Findings

The analysis led to four themes revealing that participants were motivated to RTW while struggling with impairments in the RTW process. The RTW process evoked mixed feelings of worry and grief over lost functions but also acceptance and gratitude for being able to work. Although maintaining work 7-8 years after stroke, most were restricted in some way. Fatigue and cognitive impairments meant having to set limits, omit work tasks, and rest at work but also rest during spare time and omit social activities to manage work life. Participants avoided work related stress if they could because of aggravated symptoms and/or fear of a new stroke. Support from supervisors and colleagues was often crucial for a sustainable work situation, but when not supported or even discouraged at work, it could mean a lonesome struggle enduring impairments and stress related symptoms while pushing their limits to manage work demands.

Strengths and limitations

A strength of this study was that the interview guide was developed in cooperation with a patient representative from the Swedish Stroke Association with whom a pilot interview was conducted. Another strength was the heterogeneity of the study population, representing a wide range of occupations, stroke characteristics, and social backgrounds. The participants gave rich interviews and contributed with a wide range of experiences. In the analysis process, two authors with different professional backgrounds (medical social worker and physiotherapist) coded separately and then jointly, ensuring a thorough coding process with the aim of capturing all relevant data. When developing, revising, and refining themes, open discussions on coherency, consistency, and distinctiveness led to consensus among all three authors which contributed to the credibility of the study.[15] When invited to a meeting (participant checking), participants gave feedback on the results which were taken into account and gave further credibility to the interpretations. A limitation of this study was that it only considered the perspective of persons who had RTW after stroke, and not included other stakeholders in the RTW process. Also, this study was performed in the Swedish context and the transferability of results to other cultural contexts needs consideration.

Comparison with existing literature and guidelines

In this study, we gained a profound perspective of RTW from the view of persons with stroke who had managed to RTW and stay at work for many years. Work seemed to be important to the participants, who were all motivated to RTW. This can be interpreted in the light of previous findings stating work as an important part of life, identity, and social context.[17] Being motivated to RTW has also been found to be a facilitator for RTW after stroke from an employer perspective.[18] However, high ambitions in the RTW process could generate setbacks, as shown in this study.

Disagreements with doctors, employers, or family members could be a concern when readiness for RTW is uncertain which has also previously been reported.[19] The importance of achieving appropriate, gradual RTW in combination with formal adjustments provided by the employer needs to be addressed, as previously suggested.[11]

Although having successfully RTW and still working 7-8 years after stroke, life was often restricted for participants in this study. Setting limits at work, omitting leisure- and social activities to meet an excessive need for rest, as well as trying to avoid work related stress were central strategies used to manage work life, in line with previous findings.[12] Consequently, this could mean prioritizing work and rest, having no spare energy for other life activities. On the other hand, having gained a more relaxed approach to work after stroke, some participants prioritized wellbeing and leisure activities and were content with a less senior work role or with working part-time when possible. The importance of work for wellbeing and life satisfaction after stroke has been emphasized.[14] We argue that maintaining work could be a continuous struggle many years after stroke and the use and success of coping strategies are dependent on each individual work situation, where the question of support from employers has a great impact on working conditions.

Some felt supported by their employer and others did not, maintaining work life at the expense of their own wellbeing, which could lead to the risk of future resignation, as previously presented.[12] Receiving no support from their employer could be related to difficulties in communicating impairments and adjustment needs, in particular when impairments were invisible, such as cognitive difficulties and fatigue. This could be a concern for managing work in the long run, as hidden impairments acting as key barriers for RTW has previously been suggested.[11] Employers' lack of medical knowledge, especially regarding cognitive impairments, could restrict them in making adequate adjustments.[13] Apart from gaining stroke specific knowledge from their employee, employers have used the internet as their primary source of information.[18] Thus, the communication of impairments and needs for adjustments to the employer seems crucial for receiving the support needed in the RTW process. To facilitate this communication, a stroke coordinator, who would support patients and stakeholders during the RTW process, has been suggested.[13, 20]

Clinical and policy implications

In this study, most participants had a mild stroke and were discharged from the hospital directly to their homes. Nevertheless, most still experienced cognitive impairments and fatigue that interfered with work life many years later. Cognitive impairments persisting for many years after stroke, also in people with mild stroke, have been presented previously.[21] Further, cognitive function has been found to predict RTW in people with mild to moderate stroke,[22] and although returning to work,

people with mild stroke have been reported not to be able to perform their jobs as previously due to cognitive impairments.[23] However, cognitive rehabilitation interventions have focused little on this group.[22, 24] In relation to this and the findings of our study, we suggest that more attention should be given to rehabilitation of the invisible cognitive impairments experienced by people with mild to moderate stroke in the RTW process. However, a systematic review of RTW interventions found the evidence of effectiveness of cognitive rehabilitation by itself or along with work-directed interventions to be low for people with acquired brain injury.[25]

Based on the results of our study and previous findings, the strategies used to cope with invisible impairments in the RTW process after stroke seem to be essential.[11, 12] Development of strategies such as balancing activity and rest, setting limits, and avoiding work related stress could be supported by stroke rehabilitation teams. However, interventions for managing fatigue after stroke have insufficient evidence.[26]

It seems important to encourage patients to contact their workplace early in order to facilitate communication about their individual impairments and needs in the RTW process, to receive adjustments and social support from their employer. Rehabilitation meetings with the patient and involved stakeholders could be a forum for such information sharing. In line with our suggestion, there is strong evidence for the effect of interventions including a combination of work-directed components and education/coaching on RTW.[25]

Future research

Investigating aspects of work life many years after stroke, quantitative studies or studies using mixed methods to combine patient perspectives with quantitative data on work stability, cognitive impairments, and fatigue would add generalizable knowledge.

Randomized controlled trials focusing on strategies to cope with, and communicate cognitive impairments and fatigue in the RTW process for persons with mild to moderate stroke are called for. Interventions could be based on strategies for managing work life after stroke as presented in this study.

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Author contribution

AP, MT, and KSS contributed to the design of the study. AP conducted and transcribed the interviews and analyzed the data together with MT, involving KSS in the final stages of analysis. AP and MT wrote the first version of the manuscript, which was reviewed by KSS. All three authors contributed to and approved the final manuscript.

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Competing interests

None declared.

Data sharing

Due to ethical restrictions, data are available upon request. Interested researchers may submit requests for data to the authors (contact: ks.sunnerhagen@neuro.gu.se). Complete interview data cannot be made publicly available for ethical and legal reasons, according to the Swedish regulations http://www.epn.se/en/start/regulations/. Public availability would compromise participant confidentiality or privacy. Upon request a list of condensed meaning units or codes can be made available after removal of details that may risk the confidentiality of the participants. To access such data please contact the first author: (annie.palstam@gu.se).

REFERENCES

1 Young AE, Roessler RT, Wasiak R, et al. A developmental conceptualization of return to work. *Journal of occupational rehabilitation* 2005;15(4):557-68.
2 Riksstroke (the Swedish Stroke Resister). Yearly report (Acute-, TIA- and 3 month follow-up). 2015. Available from: www.riksstroke.org/wp-content/uploads/2015/12/Strokerapport_AKUT-TIA_LR.pdf.
3 Hannerz H, Holbaek Pedersen B, Poulsen OM, et al. A nationwide prospective cohort study on return to gainful occupation after stroke in Denmark 1996-2006. *BMJ Open* 2011;1(2):e000180.
4 Larsen LP, Biering K, Johnsen SP, et al. Self-rated health and return to work after first-time stroke. *J Rehabil Med* 2016;48(4):339-45.
5 Endo M, Sairenchi T, Kojimahara N, et al. Sickness absence and return to work among Japanese stroke survivors: a 365-day cohort study. *BMJ Open* 2016;6(1):e009682.

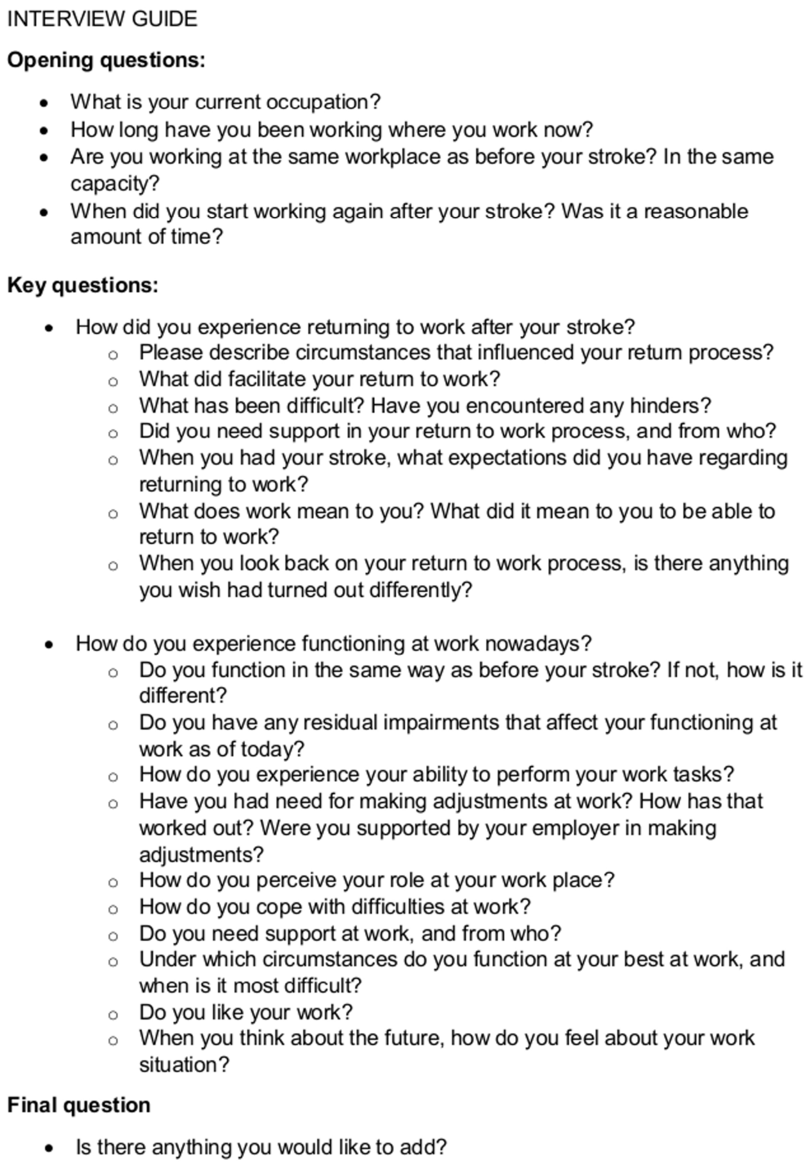
6 Glader EL, Jonsson B, Norrving B, et al. Socioeconomic factors' effect on return to work after first stroke. *Acta neurologica Scandinavica* 2017;135(6):608-13.
7 Westerlind E, Persson HC, Sunnerhagen KS. Return to Work after a Stroke in Working Age Persons; A Six-Year Follow Up. *PLoS One* 2017;12(1):e0169759.
8 Cancelliere C, Donovan J, Stochkendahl MJ, et al. Factors affecting return to work after injury or illness: best evidence synthesis of systematic reviews. *Chiropractic & manual therapies* 2016;24(1):32.
9 Wang YC, Kapellusch J, Garg A. Important factors influencing the return to work after stroke. *Work (Reading, Mass)* 2014;47(4):553-9.
10 Virtanen M, Ervasti J, Mittendorfer-Rutz E, et al. Work disability before and after a major cardiovascular event: a ten-year study using nationwide medical and insurance registers. *Scientific reports* 2017;7(1):1142.
11 Schwarz B, Claros-Salinas D, Streibelt M. Meta-Synthesis of Qualitative Research on Facilitators and Barriers of Return to Work After Stroke. *J Occup Rehabil* 2017.
12 Balasooriya-Smeekens C, Bateman A, Mant J, et al. Barriers and facilitators to staying in work after stroke: insight from an online forum. *BMJ Open* 2016;6(4):e009974.
13 Hellman T, Bergstrom A, Eriksson G, et al. Return to work after stroke: Important aspects shared and contrasted by five stakeholder groups. *Work (Reading, Mass)* 2016;55(4):901-11.
14 Vestling M, Tufvesson B, Iwarsson S. Indicators for return to work after stroke and the importance of work for subjective well-being and life satisfaction. *Journal of Rehabilitation Medicine* 2003;35(3):127-31.
15 Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative research in psychology* 2006;3(2):77-101.
16 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care : journal of the International Society for Quality in Health Care* 2007;19(6):349-57.
17 Christiansen CH. Defining lives: Occupation as identity: An essay on competence, coherence, and the creation of meaning. *American Journal of Occupational Therapy* 1999;53(6):547-58.
18 Coole C, Radford K, Grant M, et al. Returning to work after stroke: perspectives of employer stakeholders, a qualitative study. *J Occup Rehabil* 2013;23(3):406-18.
19 Gilworth G, Phil M, Cert A, et al. Personal experiences of returning to work following stroke: An exploratory study. *Work (Reading, Mass)* 2009;34(1):95-103.
20 Ost Nilsson A, Eriksson G, Johansson U, et al. Experiences of the return to work process after stroke while participating in a person-centred rehabilitation programme. *Scand J Occup Ther* 2017;24(5):349-56.

21 Ytterberg C, Dyback M, Bergstrom A, et al. Perceived impact of stroke six years after onset, and changes in impact between one and six years. *J Rehabil Med* 2017;49(8):637-43.
22 van der Kemp J, Kruithof WJ, Nijboer TC, et al. Return to work after mild-to-moderate stroke: work satisfaction and predictive factors. *Neuropsychological Rehabilitation* 2017:1-16.
23 O'Brien AN, Wolf TJ. Determining work outcomes in mild to moderate stroke survivors. *Work (Reading, Mass)* 2010;36(4):441-7.
24 Faux SG, Arora P, Shiner CT, et al. Rehabilitation and education are underutilized for mild stroke and TIA sufferers. *Disabil Rehabil* 2017:1-5.
25 Donker-Cools BH, Daams JG, Wind H, et al. Effective return-to-work interventions after acquired brain injury: A systematic review. *Brain Inj* 2016;30(2):113-31.
26 Hinkle JL, Becker KJ, Kim JS, et al. Poststroke Fatigue: Emerging Evidence and Approaches to Management: A Scientific Statement for Healthcare Professionals From the American Heart Association. *Stroke* 2017;48(7):e159-e70.

Figure legends

Figure 1. The interview guide.

Figure 2. The themes and sub-themes developed in the analysis.



INTERVIEW GUIDE

Opening questions:

- What is your current occupation?
- How long have you been working where you work now?
- Are you working at the same workplace as before your stroke? In the same capacity?
- When did you start working again after your stroke? Was it a reasonable amount of time?

Key questions:

- How did you experience returning to work after your stroke?
    - Please describe circumstances that influenced your return process?
    - What did facilitate your return to work?
    - What has been difficult? Have you encountered any hinders?
    - Did you need support in your return to work process, and from who?
    - When you had your stroke, what expectations did you have regarding returning to work?
    - What does work mean to you? What did it mean to you to be able to return to work?
    - When you look back on your return to work process, is there anything you wish had turned out differently?

- How do you experience functioning at work nowadays?
    - Do you function in the same way as before your stroke? If not, how is it different?
    - Do you have any residual impairments that affect your functioning at work as of today?
    - How do you experience your ability to perform your work tasks?
    - Have you had need for making adjustments at work? How has that worked out? Were you supported by your employer in making adjustments?
    - How do you perceive your role at your work place?
    - How do you cope with difficulties at work?
    - Do you need support at work, and from who?
    - Under which circumstances do you function at your best at work, and when is it most difficult?
    - Do you like your work?
    - When you think about the future, how do you feel about your work situation?

Final question

- Is there anything you would like to add?

Figure 1. The interview guide.

106x142mm (600 x 600 DPI)

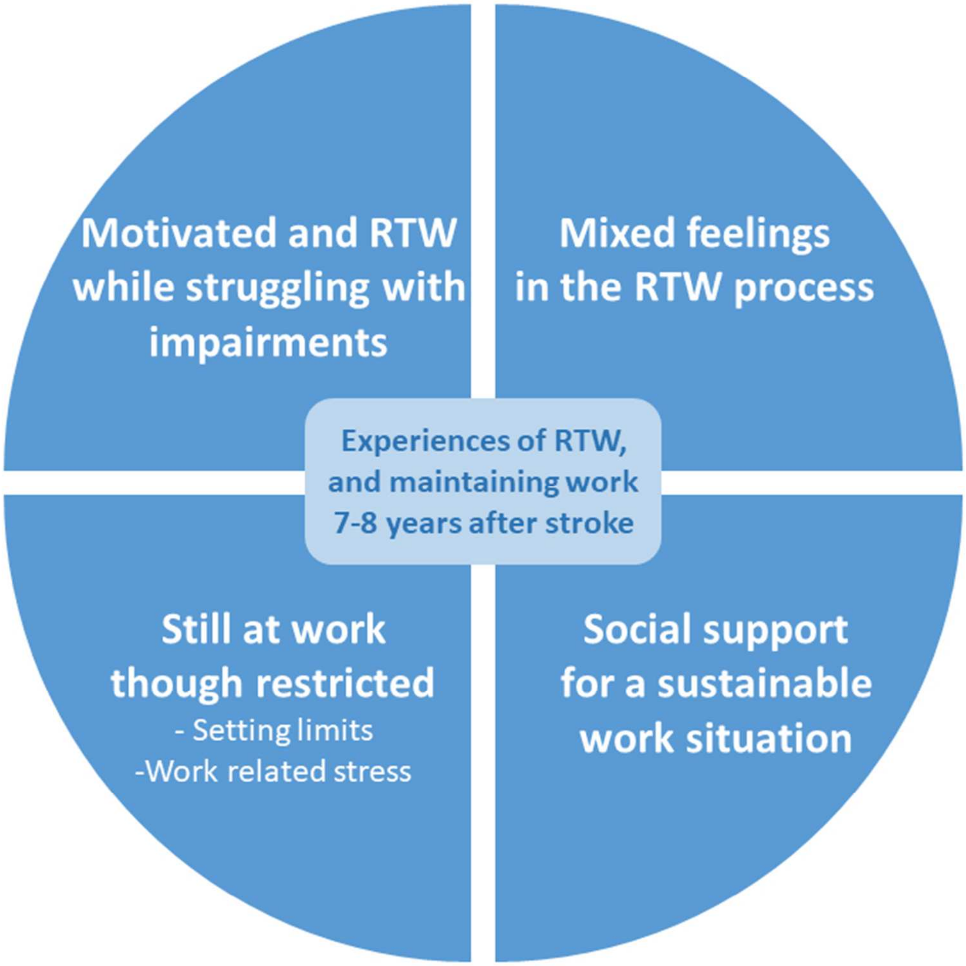


Figure 2. Themes and sub-themes developed in the analysis.

59x60mm (300 x 300 DPI)

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Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups

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Abstract

Background. Qualitative research explores complex phenomena encountered by clinicians, health care providers, policy makers and consumers. Although partial checklists are available, no consolidated reporting framework exists for any type of qualitative design.

Objective. To develop a checklist for explicit and comprehensive reporting of qualitative studies (indepth interviews and focus groups).

Methods. We performed a comprehensive search in Cochrane and Campbell Protocols, Medline, CINAHL, systematic reviews of qualitative studies, author or reviewer guidelines of major medical journals and reference lists of relevant publications for existing checklists used to assess qualitative studies. Seventy-six items from 22 checklists were compiled into a comprehensive list. All items were grouped into three domains: (i) research team and reflexivity, (ii) study design and (iii) data analysis and reporting. Duplicate items and those that were ambiguous, too broadly defined and impractical to assess were removed.

Results. Items most frequently included in the checklists related to sampling method, setting for data collection, method of data collection, respondent validation of findings, method of recording data, description of the derivation of themes and inclusion of supporting quotations. We grouped all items into three domains: (i) research team and reflexivity, (ii) study design and (iii) data analysis and reporting.

Conclusions. The criteria included in COREQ, a 32-item checklist, can help researchers to report important aspects of the research team, study methods, context of the study, findings, analysis and interpretations.

Keywords: focus groups, interviews, qualitative research, research design

Qualitative research explores complex phenomena encountered by clinicians, health care providers, policy makers and consumers in health care. Poorly designed studies and inadequate reporting can lead to inappropriate application of qualitative research in decision-making, health care, health policy and future research.

Formal reporting guidelines have been developed for randomized controlled trials (CONSORT) [1], diagnostic test studies (STARD), meta-analysis of RCTs (QUOROM) [2], observational studies (STROBE) [3] and meta-analyses of observational studies (MOOSE) [4]. These aim to improve the quality of reporting these study types and allow readers to better understand the design, conduct, analysis and findings of published studies. This process allows users of published research to be more fuller informed when they critically appraise studies relevant to each checklist and decide upon applicability of research findings to their local settings. Empiric studies have shown that the use of the CONSORT statement is associated with improvements in the quality of reports of randomized controlled trials [5]. Systematic reviews of qualitative research almost always show that key aspects of study design are not reported, and so there is a clear need for a CONSORT-equivalent for qualitative research [6].

The Uniform Requirements for Manuscripts Submitted to Biomedical Journals published by the International Committee of Medical Journal Editors (ICMJE) do not provide reporting guidelines for qualitative studies. Of all the mainstream biomedical journals (Fig. 1), only the British Medical Journal (BMJ) has criteria for reviewing qualitative research. However, the guidelines for authors specifically record that the checklist is not routinely used. In addition, the checklist is not comprehensive and does not provide specific guidance to assess some of the criteria. Although checklists for critical appraisal are available for qualitative research, there is no widely endorsed reporting framework for any type of qualitative research [7].

We have developed a formal reporting checklist for in-depth interviews and focus groups, the most common methods for data collection in qualitative health research.

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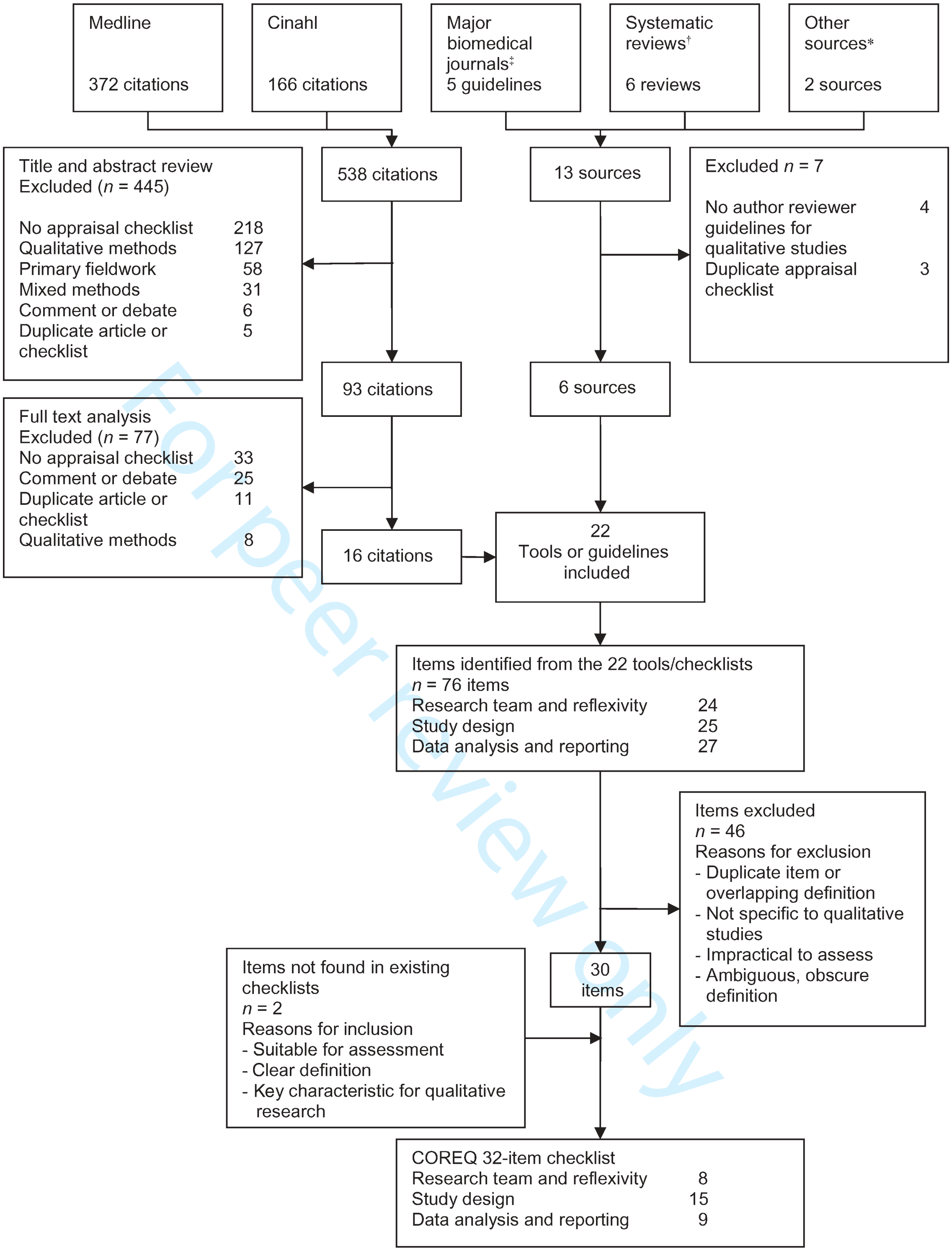

Figure 1 Development of the COREQ Checklist. *References [26, 27], †References [6, 28–32], ‡Author and reviewer guidelines provided by BMJ, JAMA, Lancet, Annals of Internal Medicine, NEJM.

These two methods are particularly useful for eliciting patient and consumer priorities and needs to improve the quality of health care [8]. The checklist aims to promote complete and transparent reporting among researchers and indirectly improve the rigor, comprehensiveness and credibility of interview and focus-group studies.

Basic definitions

Qualitative studies use non-quantitative methods to contribute new knowledge and to provide new perspectives in health care. Although qualitative research encompasses a broad range of study methods, most qualitative research publications in health care describe the use of interviews and focus groups [8].

Interviews

In-depth and semi-structured interviews explore the experiences of participants and the meanings they attribute to them. Researchers encourage participants to talk about issues pertinent to the research question by asking open-ended questions, usually in one-to-one interviews. The interviewer might re-word, re-order or clarify the questions to further investigate topics introduced by the respondent. In qualitative health research, in-depth interviews are often used to study the experiences and meanings of disease, and to explore personal and sensitive themes. They can also help to identify potentially modifiable factors for improving health care [9].

Focus groups

Focus groups are semi-structured discussions with groups of 4–12 people that aim to explore a specific set of issues [10]. Moderators often commence the focus group by asking broad questions about the topic of interest, before asking the focal questions. Although participants individually answer the facilitator's questions, they are encouraged to talk and interact with each other [11]. This technique is built on the notion that the group interaction encourages respondents to explore and clarify individual and shared perspectives [12]. Focus groups are used to explore views on health issues, programs, interventions and research.

Methods

Development of a checklist

Search strategy. We performed a comprehensive search for published checklists used to assess or review qualitative studies, and guidelines for reporting qualitative studies in: Medline (1966—Week 1 April 2006), CINAHL (1982—Week 3 April 2006), Cochrane and Campbell protocols, systematic reviews of qualitative studies, author or reviewer guidelines of major medical journals and reference lists of relevant publications. We identified the terms used to index the relevant articles already in our possession and performed a broad search using those search terms. The electronic databases were searched using terms and text words for research (standards), health services research (standards) and qualitative studies (evaluation). Duplicate checklists and detailed instructions for conducting and analysing qualitative studies were excluded.

Data extraction. From each of the included publications, we extracted all criteria for assessing or reporting qualitative studies. Seventy-six items from 22 checklists were compiled into a comprehensive list. We recorded the frequency of each item across all the publications. Items most frequently included in the checklists related to sampling method, setting for data collection, method of data collection, respondent validation of findings, method of recording data, description of the derivation of themes and inclusion of supporting quotations. We grouped all items into three domains: (i) research team and reflexivity, (ii) study design and (iii) data analysis and reporting. (see Tables 2–4)

Within each domain we simplified all relevant items by removing duplicates and those that were ambiguous, too broadly defined, not specific to qualitative research, or impractical to assess. Where necessary, the remaining items were rephrased for clarity. Based upon consensus among the authors, two new items that were considered relevant for reporting qualitative research were added. The two new items were identifying the authors who conducted the interview or focus group and reporting the presence of non-participants during the interview or focus group. The COREQ checklist for explicit and comprehensive reporting of qualitative studies consists of 32 criteria, with a descriptor to supplement each item (Table 1).

COREQ: content and rationale (see Tables 1)

Domain 1: research team and reflexivity

(i) Personal characteristics: Qualitative researchers closely engage with the research process and participants and are therefore unable to completely avoid personal bias. Instead researchers should recognize and clarify for readers their identity, credentials, occupation, gender, experience and training. Subsequently this improves the credibility of the findings by giving readers the ability to assess how these factors might have influenced the researchers' observations and interpretations [13–15].

(ii) Relationship with participants: The relationship and extent of interaction between the researcher and their participants should be described as it can have an effect on the participants' responses and also on the researchers' understanding of the phenomena [16]. For example, a clinician–researcher may have a deep understanding of patients' issues but their involvement in patient care may inhibit frank discussion with patient–participants when patients believe that their responses will affect their treatment. For transparency, the investigator should identify and state their assumptions and personal interests in the research topic.

Domain 2: study design

(i) Theoretical framework: Researchers should clarify the theoretical frameworks underpinning their study so readers can understand how the researchers explored their research questions and aims. Theoretical frameworks in qualitative research include: grounded theory, to build theories from the data; ethnography, to understand the culture of groups with shared characteristics; phenomenology, to describe the meaning and significance of experiences; discourse analysis, to analyse linguistic expression; and content analysis, to systematically organize data into a structured format [10].

Table 1 Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*
3.	Occupation	What was their occupation at the time of the study?
4.	Gender	Was the researcher male or female?
5.	Experience and training	What experience or training did the researcher have?
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement?
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*
Participant selection		
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*
12.	Sample size	How many participants were in the study?
13.	Non-participation	How many people refused to participate or dropped out? Reasons?
Setting		
14.	Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace*
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*
Data collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?
20.	Field notes	Were field notes made during and/or after the interview or focus group?
21.	Duration	What was the duration of the interviews or focus group?
22.	Data saturation	Was data saturation discussed?
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?
Domain 3: analysis and findingsz		
Data analysis		
24.	Number of data coders	How many data coders coded the data?
25.	Description of the coding tree	Did authors provide a description of the coding tree?
26.	Derivation of themes	Were themes identified in advance or derived from the data?
27.	Software	What software, if applicable, was used to manage the data?
28.	Participant checking	Did participants provide feedback on the findings?
Reporting		
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g. participant number*
30.	Data and findings consistent	Was there consistency between the data presented and the findings?
31.	Clarity of major themes	Were major themes clearly presented in the findings?
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?

(ii) Participant selection: Researchers should report how participants were selected. Usually purposive sampling is used which involves selecting participants who share particular characteristics and have the potential to provide rich, relevant and diverse data pertinent to the research question [13, 17]. Convenience sampling is less optimal because it may fail to capture important perspectives from difficult-to-reach people [16]. Rigorous attempts to recruit participants and reasons for non-participation should be stated to reduce the likelihood of making unsupported statements [18].

Table 2 Items included in 22 published checklists: Research team and reflexivity domain

Item	References																				
	[26][a]	[27][a]	[6][b]	[28][b]	[32][b]	[13]	[15]	[14]	[17]	[33]	[34]	[35]	[16]	[19]	[36]	[7]	[37]	[23]	[38]	[39]	[22]	BMJ
Research team and reflexivity																						
Nature of relationship between the researcher and participants		●		●	●		●		●						●				●			
Examination of role, bias, influence	●	●			●	●	●	●							●						●	
Description of role		●		●					●	●				●	●					●	●	
Identity of the interviewer		●		●		●					●		●		●							
Continued and prolonged engagement		●				●							●	●					●	●		
Response to events	●	●				●	●	●														
Prior assumptions and experience		●						●									●			●		
Professional status		●					●								●							
Journal, record of personal experience		●								●				●								
Effects of research on researcher		●				●	●															
Qualifications		●													●							
Training of the interviewer/facilitator			●		●																	
Expertise demonstrated		●																	●			
Perception of research at inception								●						●								
Age							●															
Gender							●															
Social class							●															
Reasons for conducting study		●																				
Sufficient contact													●									
Too close to participants													●									
Empathy																	●					
Distance between researcher and participants							●															
Background								●														
Familiarity with setting																					●	

[a]Other publications, [b]Systematic review of qualitative studies; BMJ, British Medical Journal—editor's checklist for appraising qualitative research); ●, item included in the checklist.

Table 3 Items included in 22 published checklists: Study design

Item	References [26][a]	[27][a]	[6][b]	[28][b]	[32][b]	[13]	[15]	[14]	[17]	[33]	[34]	[35]	[16]	[19]	[36]	[7]	[37]	[23]	[38]	[39]	[22]	BMJ
Study design																						
Methodological orientation, ontological or epistemological basis		●		●				●	●					●					●	●	●	●
Sampling—convenience, purposive	●	●			●	●	●	●	●	●	●	●	●	●		●		●	●	●	●	●
Setting		●		●	●			●			●				●					●		
Characteristics and description of sample		●			●			●			●		●	●								
Reasons for participant selection	●	●				●		●			●											
Non-participation	●	●		●	●																	
Inclusion and exclusion, criteria		●			●	●													●			
Identity of the person responsible for recruitment				●	●						●				●							
Sample size		●		●	●						●										●	
Method of approach		●									●					●						
Description of explanation of research to participants	●				●										●							
Level and type of participation														●								
Method of data collection, e.g. focus group, in-depth interview	●	●	●	●	●	●		●	●		●	●	●	●		●				●	●	
Audio and visual recording	●	●	●	●	●	●				●	●		●						●		●	●
Transcripts			●	●	●	●			●		●		●						●			●
Setting and location	●	●		●	●		●		●		●				●						●	●
Saturation of data	●	●	●			●			●				●	●							●	
Use of a topic guide, tools, questions	●	●	●								●					●			●	●		
Field notes			●	●	●	●													●			●
Changes and modifications	●	●		●	●														●		●	
Duration of interview, focus group		●				●					●									●		
Sensitive to participant language and views		●										●		●								
Number of interviews, focus groups		●				●																
Time span																					●	
Time and resources available to the study		●																				

[a]Other publications, [b]Systematic review of qualitative studies; BMJ, British Medical Journal—editor's checklist for appraising qualitative research; ●, item included in the checklist.

Table 4 Items included in 22 published checklists: Analysis and reporting

Item	References																					
	[26][a]	[27][a]	[6][b]	[28][b]	[32][b]	[13]	[15]	[14]	[17]	[33]	[34]	[35]	[16]	[19]	[36]	[7]	[37]	[23]	[38]	[39]	[22]	BMJ
Respondent validation	●	●	●		●		●		●	●			●	●			●	●	●	●		
Limitations and generalizability	●	●		●	●		●		●		●		●	●				●	●			
Triangulation	●	●		●	●	●	●	●	●					●			●		●			
Original data, quotation		●	●	●	●			●	●		●			●		●				●	●	●
Derivation of themes explicit	●	●	●	●	●		●	●			●								●			●
Contradictory, diverse, negative cases	●	●		●	●		●			●				●					●			●
Number of data analysts	●	●	●			●			●			●	●						●			●
In-depth description of analysis	●			●	●			●			●			●							●	●
Sufficient supporting data presented	●	●		●	●		●				●					●						
Data, interpretation and conclusions linked and integrated		●		●	●							●		●						●		
Retain context of data		●					●	●						●					●			
Explicit findings, presented clearly	●	●		●					●	●												
Outside checks													●	●				●	●			
Software used		●				●													●			●
Discussion both for and against the researchers' arguments	●	●		●	●																	
Development of theories, explanations		●					●			●		●										
Numerical data		●									●							●				●
Coding tree or coding system		●					●												●		●	
Inter-observer reliability		●									●										●	
Sufficient insight into meaning/perceptions of participants		●								●												
Reasons for selection of data to support findings		●			●																	
New insight		●						●														
Results interpreted in credible, innovative way									●													
Eliminate other theories													●									
Range of views														●								
Distinguish between researcher and participant voices								●														
Proportion of data taken into account														●								

[a]Other publications, [b]Systematic review of qualitative studies; BMJ, British Medical Journal—editor's checklist for appraising qualitative research, ●, item included in the checklist.

Researchers should report the sample size of their study to enable readers to assess the diversity of perspectives included.

(iii) Setting: Researchers should describe the context in which the data were collected because it illuminates why participants responded in a particular way. For instance, participants might be more reserved and feel disempowered talking in a hospital setting. The presence of non-participants during interviews or focus groups should be reported as this can also affect the opinions expressed by participants. For example, parent interviewees might be reluctant to talk on sensitive topics if their children are present. Participant characteristics, such as basic demographic data, should be reported so readers can consider the relevance of the findings and interpretations to their own situation. This also allows readers to assess whether perspectives from different groups were explored and compared, such as patients and health care providers [13, 19].

(iv) Data collection: The questions and prompts used in data collection should be provided to enhance the readers' understanding of the researcher's focus and to give readers the ability to assess whether participants were encouraged to openly convey their viewpoints. Researchers should also report whether repeat interviews were conducted as this can influence the rapport developed between the researcher and participants and affect the richness of data obtained. The method of recording the participants' words should be reported. Generally, audio recording and transcription more accurately reflect the participants' views than contemporaneous researcher notes, more so if participants checked their own transcript for accuracy [19–21]. Reasons for not audio recording should be provided. In addition, field notes maintain contextual details and non-verbal expressions for data analysis and interpretation [19, 22]. Duration of the interview or focus group should be reported as this affects the amount of data obtained. Researchers should also clarify whether participants were recruited until no new relevant knowledge was being obtained from new participants (data saturation) [23, 24].

Domain 3: analysis and findings

(i) Data analysis: Specifying the use of multiple coders or other methods of researcher triangulation can indicate a broader and more complex understanding of the phenomenon. The credibility of the findings can be assessed if the process of coding (selecting significant sections from participant statements), and the derivation and identification of themes are made explicit. Descriptions of coding and memoing demonstrate how the researchers perceived, examined and developed their understanding of the data [17, 19]. Researchers sometimes use software packages to assist with storage, searching and coding of qualitative data. In addition, obtaining feedback from participants on the research findings adds validity to the researcher's interpretations by ensuring that the participants' own meanings and perspectives are represented and not curtailed by the researchers' own agenda and knowledge [23].

(ii) Reporting: If supporting quotations are provided, researchers should include quotations from different participants to add transparency and trustworthiness to their findings and interpretations of the data [17]. Readers should be able to assess the consistency between the data presented and the study findings, including the both major and minor themes. Summary findings, interpretations and theories generated should be clearly presented in qualitative research publications.

Discussion

The COREQ checklist was developed to promote explicit and comprehensive reporting of qualitative studies (interviews and focus groups). The checklist consists of items specific to reporting qualitative studies and precludes generic criteria that are applicable to all types of research reports. COREQ is a comprehensive checklist that covers necessary components of study design, which should be reported. The criteria included in the checklist can help researchers to report important aspects of the research team, study methods, context of the study, findings, analysis and interpretations.

At present, we acknowledge there is no empiric basis that shows that the introduction of COREQ will improve the quality of reporting of qualitative research. However this is no different than when CONSORT, QUOROM and other reporting checklists were introduced. Subsequent research has shown that these checklists have improved the quality of reporting of study types relevant to each checklist [5, 25], and we believe that the effect of COREQ is likely to be similar. Despite differences in the objectives and methods of quantitative and qualitative methods, the underlying aim of transparency in research methods and, at the least, the theoretical possibility of the reader being able to duplicate the study methods should be the aims of both methodological approaches. There is a perception among research funding agencies, clinicians and policy makers, that qualitative research is 'second class' research. Initiatives like COREQ are designed to encourage improvement in the quality of reporting of qualitative studies, which will indirectly lead to improved conduct, and greater recognition of qualitative research as inherently equal scientific endeavor compared with quantitative research that is used to assess the quality and safety of health care. We invite readers to comment on COREQ to improve the checklist.

References

1. Moher D, Schulz KF, Altman D. The CONSORT statement: revised recommendations for improving the quality of reports of parallel-group randomized trials. *JAMA* 2001;**285**:1987–91.
2. Moher D, Cook DJ, Eastwood S *et al.* Improving the quality of reports of meta-analyses of randomised controlled trials: the QUOROM statement. Quality of Reporting of Meta-analyses. *Lancet* 1999;**354**:1896–900.

3. STROBE Statement: Strengthening the reporting of observational studies in epidemiology. http://www.strobe-statement.org/Checkliste.html
4. Stroup DF, Berlin JA, Morton SC *et al.* Meta-analysis of observational studies in epidemiology: a proposal for reporting. Meta-analysis Of Observational Studies in Epidemiology (MOOSE) group. *JAMA* 2000;**283**:2008–12.
5. Moher D, Jones A, Lepage L. Use of the CONSORT Statement and quality of reports of randomized trials. A comparative before-and-after evaluation. *JAMA* 2001;**285**:1992–5.
6. Mills E, Jadad AR, Ross C *et al.* Systematic review of qualitative studies exploring parental beliefs and attitudes toward childhood vaccination identified common barriers to vaccination. *J Clin Epidemiol* 2005;**58**:1081–8.
7. Knafl KA, Howard NJ. Interpreting and reporting qualitative research. *Res Nurs Health* 1984;**7**:7–14.
8. Sofaer S. Qualitative research methods. *Int J Qual Health Care* 2002;**14**:329–36.
9. Wright EB, Holcombe C, Salmon P. Doctor's communication of trust, care, and respect in breast cancer: qualitative study. *BMJ* 2004;**328**:864–8.
10. Liamputtong P, Ezzy D. *Qualitative Research Methods*. 2nd edn. Melbourne, Victoria: Oxford University Press, 2005.
11. Krueger RA, Casey MA. *Focus Groups. A Practical Guide for Applied Research.* Thousand Oaks CA: Sage Publications, 2000.
12. Morgan DL. *Focus Groups as Qualitative Research.* Newbury Park, California: Sage, 1988.
13. Giacomini MK, Cook DJ. Users' guides to the medical literature XXIII. Qualitative research in health care. A. Are the results of the study valid? *JAMA* 2000;**284**:357–62.
14. Malterud K. Qualitative research:standards challenges guidelines. *Lancet* 2001;**358**:483–8.
15. Mays N, Pope C. Qualitative research in health care: assessing quality in qualitative research. *BMJ* 2000;**320**:50–2.
16. Elder NC, William L. Reading and evaluating qualitative research studies. *J Fam Pract* 1995;**41**:279–85.
17. Cote L, Turgeon J. Appraising qualitative research articles in medicine and medical education. *Med Teach* 2005;**27**:71–5.
18. Altheide D, Johnson J. Criteria for assessing interpretive validity in qualitative research. In Denzin N, Lincoln Y (eds). *Handbook of Qualitative Research.* Thousand Oaks CA: Sage Publications, 1994.
19. Fossey E, Harvey C, McDermott F *et al.* Understanding and evaluating qualitative research. *Aust N Z J Psychiatry* 2002;**36**:717–32.
20. Seale C, Silverman S. Ensuring rigour in qualitative research. *Eur J Public Health* 1997;**7**:379–84.
21. Scheff T. Single case analysis in the health sciences. *Eur J Public Health* 1995;**5**:72–4.
22. Bluff R. Evaluating qualitative research. *Br J Midwifery* 1997;**5**:232–5.
23. Popay J, Rogers A, Williams G. Rationale and standards for the systematic review of qualitative literature in health services research. *Qual Health Res* 1998;**8**:341–51.
24. Blumer H. *Critiques of Research, in the Social Sciences.* New Brunswick, NJ: Transaction Books, 1979.
25. Delaney A, Bagshaw SM, Ferland A *et al.* A systematic evaluation of the quality of meta-anlyses in the critical care literature. *Crit Care* 2005;**9**:575–82.
26. Critical Skills Appraisal Programme (CASP) 10 Questions to help you make sense of qualitative research: Milton Keynes Primary Care Trust, 2002.
27. Spencer L, Ritchie J, Lewis J *et al. Quality in Qualitative Evaluation: A Framework for Assessing Research Evidence.* London: Cabinet Office. Government Chief Social Researcher's Office, 2003.
28. Campbell R, Pound P, Pope C *et al.* Evaluating meta-ethnography: a synthesis of qualitative research on lay experience of diabetes and diabetes care. *Soc Sci Med* 2003;**56**:671–84.
29. Feder GS, Hutson M, Ramsay I *et al.* Women exposed to intimate partner violence: expectations and experiences when they encounter health care professionals: a meta-analysis of qualitative studies. *Arch Intern Med* 2006;**166**:22–37.
30. Pound P, Britten N, Morgan M *et al.* Resisting medicines: a synthesis of qualitative studies of medicine taking. *Soc Sci Med* 2005;**61**:133–55.
31. Smith LK, Pope C, Botha JL. Patients' help-seeking experiences and delay in cancer presentation: a qualitative synthesis. *Lancet* 2005;**366**:825–31.
32. Walter FM, Emery J, Braithwaite D *et al.* Lay understanding of familial risk of common chronic diseases: a systematic review and synthesis of qualitative research. *Ann Fam Med* 2004; **2**:583–94.
33. Inui TS, Frankel RM. Evaluating the quality of qualitative research: a proposal pro-term. *J Gen Intern Med* 1991;**6**:485–6.
34. Boulton M, Fitzpatrick R, Swinburn C. Qualitative research in health care: II A structured review and evaluation of studies. *J Eval Clin Pract* 1996;**2**:171–9.
35. Dixon-Woods M, Shaw RL, Agarwal S *et al.* The problem of appraising qualitative research. *Qual Saf Health Care* 2004;**13**:223–5.
36. Hoddinott P, Pill R. A review of recently published qualitative research in general practice. More methodological questions than answers? *Fam Pract* 1997;**14**:313–9.
37. Kuzel AJ, Engel JD, Addison RB *et al.* Desirable features of qualitative research. *Fam Pract Res J* 1994;**14**:369–78.
38. Treloar C, Champness S, Simpson PL *et al.* Critical appraisal checklist for qualitative research studies. *Indian J Pediatr* 2000;**67**:347–51.
39. Cesario S, Morin K, Santa-Donato A. Evaluating the level of evidence in qualitative research. *J Obstet Gynecol Neonatal Nurs* 2001;**31**:708–14.

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COREQ 32-item checklist for interviews, with page indications:

1. Interviewer: Page 7
2. Credentials: Page 7
3. Occupation: Page 7
4. Gender: Page 7
5. Experience and training: Page 7
6. Relationship established: Page 5 and 7
7. Participant knowledge of the interviewer: Page 5
8. Interviewer Characteristics: Page 5 and 7
9. Methodological orientation and theory: Page 7
10. Sampling: Page 5
11. Method of approach: Page 5
12. Sample size: Page 5
13. Non-participation: Page 5
14. Setting of data collection: Page 7
15. Presence of non-participants: Page 7
16. Description of sample: Page 5-7
17. Interview guide: Page 7 and figure 1
18. Repeat interviews: n.a.
19. Audio/visual recording: Page 7
20. Field notes: Page 7
21. Duration: Page 7
22. Data saturation: Page 7
23. Transcripts returned: Page 8
24. Number of data coders: Page 8
25. Description of the coding tree: Page 8-9
26. Derivation of themes: Page 8
27. Software: n.a.
28. Participant checking: Page 8
29. Quotations presented: Page 11-15
30. Data and findings consistent: Page 9-15
31. Clarity of major themes: Page 9 (Fig 2), page 9-15
32. Clarity of minor themes: Page 9 (Fig 2), page 9-15

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Experiences of returning to work, and maintaining work 7 to 8 years after stroke in Sweden - a qualitative interview study

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Experiences of returning to work, and maintaining work 7 to 8 years after stroke in Sweden - a qualitative interview study

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Experiences of returning to work, and maintaining work 7 to 8 years after stroke in Sweden - a qualitative interview study

ABSTRACT

Objective: To explore how persons experienced return to work (RTW) and their work situation 7 to 8 years after stroke.

Design: An explorative qualitative design with individual interviews. The data analysis was inductive thematic and three researchers cooperated during the analysis process.

Participants: The study population included five women and eight men who had a stroke during 2009-2010, received care at the Sahlgrenska University Hospital in Gothenburg, Sweden, and RTW after stroke, a heterogenic sample based on age, occupation, stroke severity, and time to RTW.

Results: The analysis led to four themes; *motivated and RTW while struggling with symptoms*, *mixed feelings in the RTW process, still at work although restricted, and social support for a sustainable work situation.* The themes revealed that participants were motivated to RTW while struggling with impairments. The RTW process evoked mixed feelings of worry and grief over lost functions but also acceptance and gratitude for being able to work. Although maintaining work 7 to 8 years after stroke, most were restricted in some way. Fatigue and cognitive impairments meant having to set limits, omit work tasks, and rest at work, but also rest during free time and omit social activities in order to manage work. Participants avoided work related stress if they could because of aggravated symptoms and/or fear of a new stroke. Support from supervisors and colleagues was often crucial for a sustainable work situation but when not supported or even discouraged at work, it could mean a lonesome struggle to endure impairments and stress related symptoms to manage work demands.

Conclusion Maintaining work can be a continuous struggle with invisible impairments many years after stroke. Strategies for managing work are dependent on each individual work situation, where support and understanding at work seem to be crucial for a sustainable work situation.

Strengths and limitations of this study (bullet points)

- The focus of this study was the perspective of persons who had worked for years since their stroke, but apart from having this in common, they represented a wide range of occupations, stroke characteristics, and social backgrounds, gave rich interviews and contributed with experiences of maintaining work life after stroke.
- The patient perspective was integrated throughout the study as the interview guide was developed in cooperation with a patient representative from the Swedish Stroke

Association, with whom a pilot interview was conducted, and further in the analysis process the participants were invited to a meeting to discuss and give feedback on the results (participant checking), which gave credibility to the interpretations.

- A limitation of this study was that it only considered the perspective of persons who had RTW after stroke, and not included other stakeholders in the RTW process.
- This study was performed in the Swedish context and the transferability of results to other cultural contexts needs consideration.

INTRODUCTION

Return to work (RTW) is commonly referred to as the event when resuming work after a period of sick leave although a broader view has been suggested to include the whole RTW process, from initial work disability to reaching ones’ full potential at work.[1] In Sweden, 25-30 000 people suffer a stroke each year, of whom 20% are of working age, an age group in which stroke has become more common in recent years.[2] The reported RTW rate between one to three years after stroke varies globally between 50 to 74 percent,[3-7] of which two Swedish studies found a RTW rate of 74%.[6, 7] In Sweden, employers have the most explicit responsibility of rehabilitation concerning their employees´ RTW, although shared with health care, the Social Insurance Office (SIO) and the Employment Agency (EA). Employers are obliged to adapt work tasks, working hours, start work trials, and make technical adjustments, though they are not forced to expand or create new work tasks. Common predictors for RTW in people with non-communicable diseases have been found to be higher socioeconomic status, higher self-efficacy, and positive expectations of recovery, less severe illness, better RTW coordination, and multidisciplinary interventions including the workplace.[8] For stroke, less severe stroke and good self-rated health have been reported to be predictors for RTW.[4] Predictors for no RTW have been reported to be physical dependency at discharge,[7] degree of residual disability,[9] sick leave-,[7] or unemployment,[10] prior to stroke, low socioeconomic status,[6] being an immigrant,[10] comorbidities,[10] older age,[5] and being female.[3]

A recent meta-synthesis of qualitative studies on RTW after stroke summarized important factors relative to RTW such as those related to rehabilitation services (availability, accessibility, and appropriateness), the person (impairments, coping, adaptation, and motivation), and the workplace (demands, adaptations, disability management, work climate, and social support).[11] Another qualitative study found that awareness of invisible impairments generated support from employers and colleagues at work and a positive work experience, whereas the opposite presented a large barrier for RTW.[12] A qualitative study suggested the importance of a coordinator for communicating information between stakeholders in the RTW process.[13] Work has been found to be of importance for well-being and life satisfaction after stroke,[14] and RTW can be seen as a strive for normality.[12] Although many studies have investigated factors influencing return or no return to work after stroke, few have studied experiences of working in the long run after stroke.

The aim of this study was to explore experiences of returning to work and maintaining work seven to eight years after stroke.

METHODS

Study design

This is an explorative qualitative study using individual interviews and inductive thematic analysis, which can be referred to a realist/essentialist paradigm.[15] The COREQ guidelines for reporting qualitative research were used.[16] The study was approved by the Regional Ethics Committee in Gothenburg, Sweden, on June 5th 2013 (Dnr: 400-13). Oral and written information was given and written informed consent was received.

Patient and Public involvement

The research question was developed with the aim of learning more about the experiences of persons who had returned to work after having had a stroke. A patient representative from the Swedish Stroke Association was involved in the development and pilot testing of the interview guide. Patients were involved in the conduct of the study, in individual interviews and when invited to a meeting to hear the results and to discuss the interpretation with the authors. The preliminary results of the analysis have been delivered to the study participants in a written letter.

Participants

Participants were identified in the Extended Stroke Arm Longitudinal study at the University of Gothenburg, SALGOT-extended. The inclusion criteria were; having suffered an ischemic or hemorrhagic stroke in the years 2009-2010, having received care at the Sahlgrenska University Hospital in Gothenburg, Sweden, residing in the Gothenburg urban area, being of working age (18-64), and having RTW after stroke. Eighty-two persons were potentially eligible and a letter including information about the purpose of the study, brief information about the clinical and research experience of the interviewer (AP) and information about the research team, was sent out to a purposive sample of 37 persons to achieve a heterogeneous study population based on age, gender, occupation, stroke severity (NIH Stroke Scale (0-46)), and time to RTW. The letter was followed up by a telephone call by AP to confirm participation and to schedule interviews. If a person was not reached by telephone, another letter was sent out encouraging the person to make contact if they were interested in participating. Fourteen persons agreed to participate, but one was excluded due to not having RTW after stroke. The participants were asked to complete a form about demographics and employment. This is presented in Table 1 together with data retrieved from medical charts.

Table 1. Demographic and clinical characteristics of the study population

	Study population (n=13)
Age, mean years (min-max)	50 (39-64)

Gender: Female/Male	 5/8
Country of birth: Sweden Middle East or African country	 10 3
Current living conditions: Living alone Living with partner/ -and children	 5 3/5
Type of stroke: Ischemic stroke Intracerebral hemorrhage	 9 4
Stroke severity (NIH Stroke Scale): Mild (0-4) Moderate (5-15) Severe (16-46)	 10 2 1
Stroke localization: Right hemisphere Left hemisphere Bilateral Not specified	 4 3 1 5
Discharged from stroke unit: Discharged home/ to rehab center	 9/4
Education: ≤ 9 years 10-12 years > 12 years	 5 3 5
Occupations:	Accountant Assistant nurse Civil Engineer Cleaner (n=2) Commander on ferry Dentist Economist Police inspector Production worker Service technician Terminal worker Vehicle fitter
Work related characteristics:	
Time to RTW (period of full time sick leave)	Range: 2 months – 2 years
Same employer as before stroke Lost job before RTW Lost job after RTW	11 1 1

Percent of employment at the time of the interview: 100% 75% 50%	 10 2 1
Employment: Employed in public sector Employed in private sector Self-employed Employed in sheltered work	 5 5 1 2

Data collection

Individual, face-to-face interviews were conducted by the first author (AP) who has a PhD in medicine, is a registered physiotherapist, has previous experience in performing qualitative studies, with no previous relation to the participants, and is a woman with interest in work ability. A semi-structured interview guide with open-ended questions was used and is presented in Figure 1.The interview guide was discussed and revised in cooperation with a patient representative from the Swedish Stroke Association with whom it was first tested in a pilot interview. Thirteen interviews were performed during April to September 2017, three took place in the participants' homes and ten at the rehabilitation medicine research unit facilities. By request of one participant, the interview was conducted in the presence of a next of kin who clarified answers due to language difficulties. The duration of interviews ranged from 40 to 90 minutes. All interviews were audio-recorded and transcribed verbatim by the first author (AP). No field notes were taken during the interviews. After 13 interviews, no new relevant knowledge was being obtained from new participants and hence, data saturation was considered to be achieved.[16]

Insert figure 1 about here

Data analysis

The transcribed interviews were analyzed by inductive thematic analysis[15] as described in Table 2.

Table 2. The steps of thematic analysis according to Braun and Clarke.[15]

Steps	Description
1	Familiarization with data: transcribing, reading, re-reading, noting down initial ideas
2	Generating initial codes: coding interesting features across the entire data set
3	Searching for themes: collecting codes into potential themes, gathering all data relevant to each potential theme

4	Reviewing themes: checking if the themes work in relation to the coded extracts and the entire data set, generating a thematic map of the analysis
5	Defining and naming themes: ongoing analysis to refine the specifics of each theme
6	Producing the report: the final opportunity for analysis, selection of vivid, compelling extract examples, relating back of the analysis to the research question and literature, producing a report of the analysis

First, the transcribed interviews were read and re-read by two of the authors (AP and MT). MT has a PhD (the first social worker with a PhD at the medical faculty) and more than 30 years of experience as a social worker and with qualitative research methodology. The interviews were read separately by the two authors to familiarize with the text and to obtain a sense of the whole. In this process, initial codes were noted separately by the two authors. Second, the authors coded the interviews together and searched for potential themes. The themes were then reviewed and refined by all three authors together and differences were discussed until consensus was reached, with the aim of enhancing the credibility of the analysis. The third author (KSS) is a MD, stroke specialist and Professor in Rehabilitation Medicine with more than 25 years of clinical and research experience in neurological diagnoses. KSS contributed with stroke specific knowledge in discussions concerning revising and refining the themes. The analysis process moved continuously back and forth between the whole and parts of the text to ensure the validity of the themes in relation to the data set. The study participants were invited to a meeting to hear the results and to discuss the interpretation with the authors. Examples of the coding process are provided in Table 3.

Table 3. Examples illustrating the coding tree

Data extract	Code	Theme
(my boss says) “I see that you are tired, you need to rest. You need a break. Sit down there in the corner in my recliner and rest, I can see it in your eyes that you need a break, so I’m ‘shutting you down’ (like a machine) a little and I’ll keep working.”	Acknowledging symptoms and encouraging rest at work	Social support for a sustainable work situation
“they warned me that I’d be fatigued and stuff like that, but I thought I could handle it quite well with the gradual steps that I took. And there were planned rest days… And then the doctor said: people manage to start working pretty well, but it’s important that you have longer recovery times, that are not broken up.”	Experience of RTW at just the right pace	Motivated and returned to work while struggling with impairments

RESULTS

Four themes were identified; *motivated and RTW while struggling with impairments*, *mixed feelings in the RTW process*, *still at work though restricted* which includes two sub-themes, and *social support for a sustainable work situation* (Fig 2). The themes are illustrated with quotes from the participants.

Insert figure 2 about here

Motivated and returned to work while struggling with impairments

Participants described a wide range of impairments that initially affected RTW (Table 4).

Full time sick leave was prescribed for all participants and lasted from two months up to two years. Motivational factors for returning to work were an urge to leave the role of sick person behind, regaining a meaningful daily activity, strong work morals and work identity, economic needs, and a strive for normality.

" The best rehabilitation for me has been starting to work again and getting away from the being sick part, and I wanted to get out and, like, meet people…. It was a way to start to function normally again." Man, 39 years

All participants returned to work gradually in an individually adjusted pace and all but one returned to their previous job, who found a new full-time job. The RTW was sometimes too early or the gradual escalation was sometimes too rapid. This was related to high ambitions in combination with impairments and resulted in setbacks, such as fatigue and emotional stress, which forced a backwards step in the RTW process. This was frustrating, but manageable when focusing on striving forwards in the RTW process. Experiences of RTW at just the right pace or later than appropriate were also reported. They were hindered by doctors, work supervisors, or family members, raising feelings of disappointment or discouragement, but also feelings of being cared for.

"they warned me that I'd be fatigued and stuff like that, but I thought I could handle it quite well with the gradual steps that I took. And there were planned rest days… And then the doctor said: people manage to start working pretty well, but it's important that you have longer recovery times, that are not broken up." Man, 58 years

In the RTW process, individual adaptations of work time, work tasks, and the work environment were performed in partnership with the employer.

"He (my boss) has given me a good room and good nurses and good support, so like, a lot of stuff around me, he has been up for making sure I have calm surroundings and a stable room and not need to change between a bunch of different nurses, I have the same ones, so he's been very supportive in that way…" Woman, 57 years

Work demands were adjusted by refraining from works tasks and responsibilities. Some described no need for adaptations and were content with their work demands.

Table 4. Impairments affecting work initially in the RTW process and 7-8 years after stroke, as expressed by participants.

Initial impairments	Residual impairments
Altered mental functions	
Disorientation in time	
Disorientation in space	
Lack of initiative	
Difficulties concentrating	Difficulties concentrating
Difficulties multitasking	Difficulties multitasking
Difficulties processing information and impressions	Difficulties processing information and impressions
Difficulties with numbers and letters	
Memory difficulties	
Depression	
Fatigue	Fatigue
Altered sensory functions and pain	
Sensitivity to sound	
Sensory loss and alterations	
Headache	Headache
Balance difficulties	Vertigo and balance difficulties
Altered neuromusculoskeletal functions	
Muscle weakness on one side of the body	Muscle weakness on one side of the body
Coordination difficulties	
Altered voice and speech functions	
Losing volume of voice	

Mixed feelings in the RTW process

Uncertainty about consequences of stroke and prognosis of recovery raised worries about the future, including work life. Speculations about whether impairments were age- or stroke-related were expressed. Expectations of a fast recovery sometimes led to disappointment later when still struggling with impairments, or to satisfaction when the recovery rate turned out as expected. Some had been told by doctors that they would fully recover but when still struggling with impairments and work tasks 7-8 years after stroke they wondered how and when that would happen. However, gratitude for functioning well despite stroke when considering how life might have turned out was expressed; they had been given a second chance in life and could work.

"I'm happy to be able to work 75%, because I had a large stroke, so the idea that I'm able to work at all, that's completely amazing." Woman, 57 years

Acceptance of impaired functions as well as a more relaxed attitude towards work life were expressed. Participants described satisfaction with regained functions, but also frustration and grief over lost functions and disappointment at having been deprived of career opportunities.

Still at work though restricted

Seven to eight years after stroke, impairments were less obvious than initially post stroke, though most participants had impairments that still interfered with work (Table 4).

Setting limits

Setting limits for colleagues, patients, and customers to create opportunities for rest and undisturbed work was one strategy used to manage work demands. It was hard, and time consuming to shift focus and get back on track with their own work tasks after being disrupted by others, forcing participants to set limits for interaction with colleagues in order to focus on their own tasks. Limiting ambition was a way to avoid fatigue, this could mean delegating work tasks or accepting a more subordinate work role. When demands on multitasking and information processing were too high, this could lead to confusion, insecurity, and refraining from work tasks. Difficulties setting limits at work were experienced when expressed needs were not heard by supervisors or colleagues. Sometimes, participants chose not to participate in social activities at work due to fatigue, forced to focus on work tasks and nothing else.

"Some days are a lot, and you get interrupted the whole time during your breaks and stuff…though I try and work around that by not going on break when everyone else does. Sometimes I've thought that my brain needs to rest a little, it's fun to sit and chat with the others so I'm part of the group, but some days I feel… I want to take the opportunity to have a break when the others have gone so I can have a little bit of peace." Woman, 48 years

When trying to keep up appearances to compete with colleagues, one participant avoided setting limits. However, some found it easier to set limits now than before their stroke, they mentioned being able to stand up for themselves and knowing more about their rights.

Independent work was described to allow for work at their own pace, providing opportunities to prepare and plan work according to their own functional level. Fatigue was described as a dominant impairment that was coped with by taking pauses at work, which was allowed for at some workplaces but not at others.

"then there's the fatigue, if I'm going to have a more complicated meeting with a customer, or if I need to have a wage renegotiation meeting or performance review, I always have them in the morning. I always plan them for the mornings, because in the afternoon I get more fatigued, unfortunately." Woman, 45 years

Gaining insight post stroke into the importance of taking care of their own health sometimes led to prioritizing physical exercise in order to be able to function better at work. But finding the energy for exercise was sometimes impossible when they were stuck in the vicious circle of fatigue and work demands. Some described exercising less than before the stroke, due to the fear of a new stroke. Participants described an excessive need for rest, before and after work. Spare time activities were often neglected due to lack of energy and were replaced by rest and sleep to manage work.

"Before I had my stroke I had an allotment, so when I was finished at work I'd go and dig and do some work there. I rode my bike there. Now I just can't manage it… I feel that things are different to before, but I want to live like that, like, I don't want to push the limits, I want to try and live the way I am able to." Man, 59 years

Work related stress

Work demands of being constantly available to customers, patients, or colleagues and a competitive work environment, lack of control of workload, and irregular inflow of work created stress. Also, having to adjust to changing work schedules, being forced to work overtime, or having to manage the same work demands as before stroke were stressful.

When exposed to stress at work, participants described having symptoms like the ones they had at stroke onset, such as sensations of numbness, tingling, and headache, which gave rise to the fear of having a new stroke.

"So every time you get a headache you start to think negatively, think if it's another thing like that that is happening (a new stroke) … before I had the stroke, you could say I was very stressed out. But

now I don't stress as much. I think, nah it will take the time it takes and not stress too much, it's just that way. So, like at work right now, you work but not as intensively as you did before, and you have to think about your own health too." Man, 46 years

The participants tried to avoid work related stress but when this proved impossible, one started his own business to regain control over his workload. Others were forced to stress at work and endured recurrent symptoms such as headache, fatigue, vertigo, or high blood pressure and felt trapped because of economic needs or were too exhausted to change jobs.

Social support for a sustainable work situation

Participants felt looked after and privileged when supported by their supervisor. A supervisor could advocate work task adaptations, acknowledge symptoms, and encourage rest at work, or could accept flexible working hours.

(my boss says) "I see that you are tired, you need to rest. You need a break. Sit down there in the corner in my recliner and rest, I can see it in your eyes that you need a break, so I'm 'shutting you down' (like a machine) a little and I'll keep working." Woman, 48 years

Some participants did not feel supported by their supervisor, who ignored them and their needs which created a strenuous work situation. One supervisor gave mixed signals, both being supportive and setting unreasonable demands at the same time. One participant had been discouraged by the supervisor at a rehabilitation meeting but stood up against the supervisor and gained support that way. One participant felt actively discouraged by the supervisor and experienced that the supervisor tried to force them to resign.

"And she, my boss, doesn't accept the doctor's certificate but it's, I don't know what to say, they're against me…In two weeks I'm going to work nights, but I…they want me to take the week off unpaid. Last time it was a late shift I took holiday leave…" Man, 59 years

Participants said that it felt safe to return to the same work team, they got along well with colleagues when they could communicate openly and joke about their symptoms at work. When impairments did not interfere with work, some appreciated being treated like anyone else, but when impairments affected work, some appreciated to be relieved of work tasks, and receive social support from colleagues.

Societal support could mean assistance from a labor union, the Swedish Social Insurance Agency, or the Employment Agency in the RTW process. One could feel supported but also exposed by contact with these authorities.

DISCUSSION

Findings

The analysis led to four themes revealing that participants were motivated to RTW while struggling with impairments in the RTW process. The RTW process evoked mixed feelings of worry and grief over lost functions but also acceptance and gratitude for being able to work. Although maintaining work 7-8 years after stroke, most were restricted in some way. Fatigue and cognitive impairments meant having to set limits, omit work tasks, and rest at work but also rest during spare time and omit social activities to manage work life. Participants avoided work related stress if they could because of aggravated symptoms and/or fear of a new stroke. Support from supervisors and colleagues was often crucial for a sustainable work situation, but when not supported or even discouraged at work, it could mean a lonesome struggle enduring impairments and stress related symptoms while pushing their limits to manage work demands.

Strengths and limitations

A strength of this study was that the interview guide was developed in cooperation with a patient representative from the Swedish Stroke Association with whom a pilot interview was conducted. Another strength was the heterogeneity of the study population, representing a wide range of occupations, stroke characteristics, and social backgrounds. The participants gave rich interviews and contributed with a wide range of experiences. In the analysis process, two authors with different professional backgrounds (medical social worker and physiotherapist) coded separately and then jointly, ensuring a thorough coding process with the aim of capturing all relevant data. When developing, revising, and refining themes, open discussions involving all three authors on coherency, consistency, and distinctiveness led to consensus which contributed to the credibility of the study.[15] When invited to a meeting (participant checking), participants gave feedback on the results which were taken into account and gave further credibility to the interpretations. A limitation of this study was that it only considered the perspective of persons who had RTW after stroke, and not included other stakeholders in the RTW process. Also, this study was performed in the Swedish context and the transferability of results to other cultural contexts needs consideration.

Comparison with existing literature and guidelines

In this study, we gained a profound perspective of RTW from the view of persons with stroke who had managed to RTW and stay at work for many years. Work seemed to be important to the participants, who were all motivated to RTW. This can be interpreted in the light of previous findings stating work as an important part of life, identity, and social context.[17] Being motivated to RTW has also been found to be a facilitator for RTW after stroke from an employer perspective.[18] However, high ambitions in the RTW process could generate setbacks, as shown in this study.

Disagreements with doctors, employers, or family members could be a concern when readiness for RTW is uncertain which has also previously been reported.[19] The importance of achieving appropriate, gradual RTW in combination with formal adjustments provided by the employer needs to be addressed, as previously suggested.[11]

Although having successfully RTW and still working 7-8 years after stroke, life was often restricted for participants in this study. Setting limits at work, omitting leisure- and social activities to meet an excessive need for rest, as well as trying to avoid work related stress were central strategies used to manage work life, in line with previous findings.[12] Consequently, this could mean prioritizing work and rest, having no spare energy for other life activities. On the other hand, having gained a more relaxed approach to work after stroke, some participants prioritized wellbeing and leisure activities and were content with a less senior work role or with working part-time when possible. The importance of work for wellbeing and life satisfaction after stroke has been emphasized.[14] We argue that maintaining work could be a continuous struggle many years after stroke and the use and success of coping strategies are dependent on each individual work situation, where the question of support from employers has a great impact on working conditions.

Some felt supported by their employer and others did not, maintaining work life at the expense of their own wellbeing, which could lead to the risk of future resignation, as previously presented.[12] Receiving no support from their employer could be related to difficulties in communicating impairments and adjustment needs, in particular when impairments were invisible, such as cognitive difficulties and fatigue. This could be a concern for managing work in the long run, as hidden impairments acting as key barriers for RTW has previously been suggested.[11] Employers' lack of medical knowledge, especially regarding cognitive impairments, could restrict them in making adequate adjustments.[13] Apart from gaining stroke specific knowledge from their employee, employers have used the internet as their primary source of information.[18] Thus, the communication of impairments and needs for adjustments to the employer seems crucial for receiving the support needed in the RTW process. To facilitate this communication, a stroke coordinator, who would support patients and stakeholders during the RTW process, has been suggested by other researchers.[13, 20]

Clinical and policy implications

In this study, most participants had a mild stroke and were discharged from the hospital directly to their homes. Nevertheless, most still experienced cognitive impairments and fatigue that interfered with work life many years later. Cognitive impairments persisting for many years after stroke, also in people with mild stroke, have been presented previously.[21] Further, cognitive function has been found to predict RTW in people with mild to moderate stroke,[22] and although returning to work,

people with mild stroke have been reported not to be able to perform their jobs as previously due to cognitive impairments.[23] However, cognitive rehabilitation interventions have focused little on this group.[22, 24] In relation to this and the findings of our study, we suggest that more attention should be given to rehabilitation of the invisible cognitive impairments experienced by people with mild to moderate stroke in the RTW process. However, a systematic review of RTW interventions found the evidence of effectiveness of cognitive rehabilitation by itself or along with work-directed interventions to be low for people with acquired brain injury.[25]

Based on the results of our study and previous findings, the strategies used to cope with invisible impairments in the RTW process after stroke seem to be essential.[11, 12] Development of strategies such as balancing activity and rest, setting limits, and avoiding work related stress could be supported by stroke rehabilitation teams. However, interventions for managing fatigue after stroke have insufficient evidence.[26]

It seems important to encourage patients to contact their workplace early in order to facilitate communication about their individual impairments and needs in the RTW process, to receive adjustments and social support from their employer. Rehabilitation meetings with the patient and involved stakeholders could be a forum for such information sharing. In line with our suggestion, there is strong evidence for the effect of interventions including a combination of work-directed components and education/coaching on RTW.[25]

Future research

Investigating aspects of work life many years after stroke, quantitative studies or studies using mixed methods to combine patient perspectives with quantitative data on work stability, cognitive impairments, and fatigue would add generalizable knowledge.

Randomized controlled trials focusing on strategies to cope with, and communicate cognitive impairments and fatigue in the RTW process for persons with mild to moderate stroke are called for. Interventions could be based on strategies for managing work life after stroke as presented in this study.

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Author contribution

AP, MT, and KSS contributed to the design of the study. AP conducted and transcribed the interviews and analyzed the data together with MT, involving KSS in the final stages of analysis. AP and MT wrote the first version of the manuscript, which was reviewed by KSS. All three authors contributed to and approved the final manuscript.

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Competing interests

None declared.

Data sharing

Due to ethical restrictions, data are available upon request. Interested researchers may submit requests for data to the authors (contact: ks.sunnerhagen@neuro.gu.se). Complete interview data cannot be made publicly available for ethical and legal reasons, according to the Swedish regulations http://www.epn.se/en/start/regulations/. Public availability would compromise participant confidentiality or privacy. Upon request a list of condensed meaning units or codes can be made available after removal of details that may risk the confidentiality of the participants. To access such data please contact the first author: (annie.palstam@gu.se).

REFERENCES

1 Young AE, Roessler RT, Wasiak R, et al. A developmental conceptualization of return to work. *Journal of occupational rehabilitation* 2005;15(4):557-68.
2 Riksstroke (the Swedish Stroke Resister). Yearly report (Acute-, TIA- and 3 month follow-up). 2015. Available from: www.riksstroke.org/wp-content/uploads/2015/12/Strokerapport_AKUT-TIA_LR.pdf.
3 Hannerz H, Holbaek Pedersen B, Poulsen OM, et al. A nationwide prospective cohort study on return to gainful occupation after stroke in Denmark 1996-2006. *BMJ Open* 2011;1(2):e000180.
4 Larsen LP, Biering K, Johnsen SP, et al. Self-rated health and return to work after first-time stroke. *J Rehabil Med* 2016;48(4):339-45.
5 Endo M, Sairenchi T, Kojimahara N, et al. Sickness absence and return to work among Japanese stroke survivors: a 365-day cohort study. *BMJ Open* 2016;6(1):e009682.

6 Glader EL, Jonsson B, Norrving B, et al. Socioeconomic factors' effect on return to work after first stroke. *Acta neurologica Scandinavica* 2017;135(6):608-13.
7 Westerlind E, Persson HC, Sunnerhagen KS. Return to Work after a Stroke in Working Age Persons; A Six-Year Follow Up. *PLoS One* 2017;12(1):e0169759.
8 Cancelliere C, Donovan J, Stochkendahl MJ, et al. Factors affecting return to work after injury or illness: best evidence synthesis of systematic reviews. *Chiropractic & manual therapies* 2016;24(1):32.
9 Wang YC, Kapellusch J, Garg A. Important factors influencing the return to work after stroke. *Work (Reading, Mass)* 2014;47(4):553-9.
10 Virtanen M, Ervasti J, Mittendorfer-Rutz E, et al. Work disability before and after a major cardiovascular event: a ten-year study using nationwide medical and insurance registers. *Scientific reports* 2017;7(1):1142.
11 Schwarz B, Claros-Salinas D, Streibelt M. Meta-Synthesis of Qualitative Research on Facilitators and Barriers of Return to Work After Stroke. *J Occup Rehabil* 2017.
12 Balasooriya-Smeekens C, Bateman A, Mant J, et al. Barriers and facilitators to staying in work after stroke: insight from an online forum. *BMJ Open* 2016;6(4):e009974.
13 Hellman T, Bergstrom A, Eriksson G, et al. Return to work after stroke: Important aspects shared and contrasted by five stakeholder groups. *Work (Reading, Mass)* 2016;55(4):901-11.
14 Vestling M, Tufvesson B, Iwarsson S. Indicators for return to work after stroke and the importance of work for subjective well-being and life satisfaction. *Journal of Rehabilitation Medicine* 2003;35(3):127-31.
15 Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative research in psychology* 2006;3(2):77-101.
16 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care : journal of the International Society for Quality in Health Care* 2007;19(6):349-57.
17 Christiansen CH. Defining lives: Occupation as identity: An essay on competence, coherence, and the creation of meaning. *American Journal of Occupational Therapy* 1999;53(6):547-58.
18 Coole C, Radford K, Grant M, et al. Returning to work after stroke: perspectives of employer stakeholders, a qualitative study. *J Occup Rehabil* 2013;23(3):406-18.
19 Gilworth G, Phil M, Cert A, et al. Personal experiences of returning to work following stroke: An exploratory study. *Work (Reading, Mass)* 2009;34(1):95-103.
20 Ost Nilsson A, Eriksson G, Johansson U, et al. Experiences of the return to work process after stroke while participating in a person-centred rehabilitation programme. *Scand J Occup Ther* 2017;24(5):349-56.

21 Ytterberg C, Dyback M, Bergstrom A, et al. Perceived impact of stroke six years after onset, and changes in impact between one and six years. *J Rehabil Med* 2017;49(8):637-43.

22 van der Kemp J, Kruithof WJ, Nijboer TC, et al. Return to work after mild-to-moderate stroke: work satisfaction and predictive factors. *Neuropsychological Rehabilitation* 2017:1-16.

23 O'Brien AN, Wolf TJ. Determining work outcomes in mild to moderate stroke survivors. *Work (Reading, Mass)* 2010;36(4):441-7.

24 Faux SG, Arora P, Shiner CT, et al. Rehabilitation and education are underutilized for mild stroke and TIA sufferers. *Disabil Rehabil* 2017:1-5.

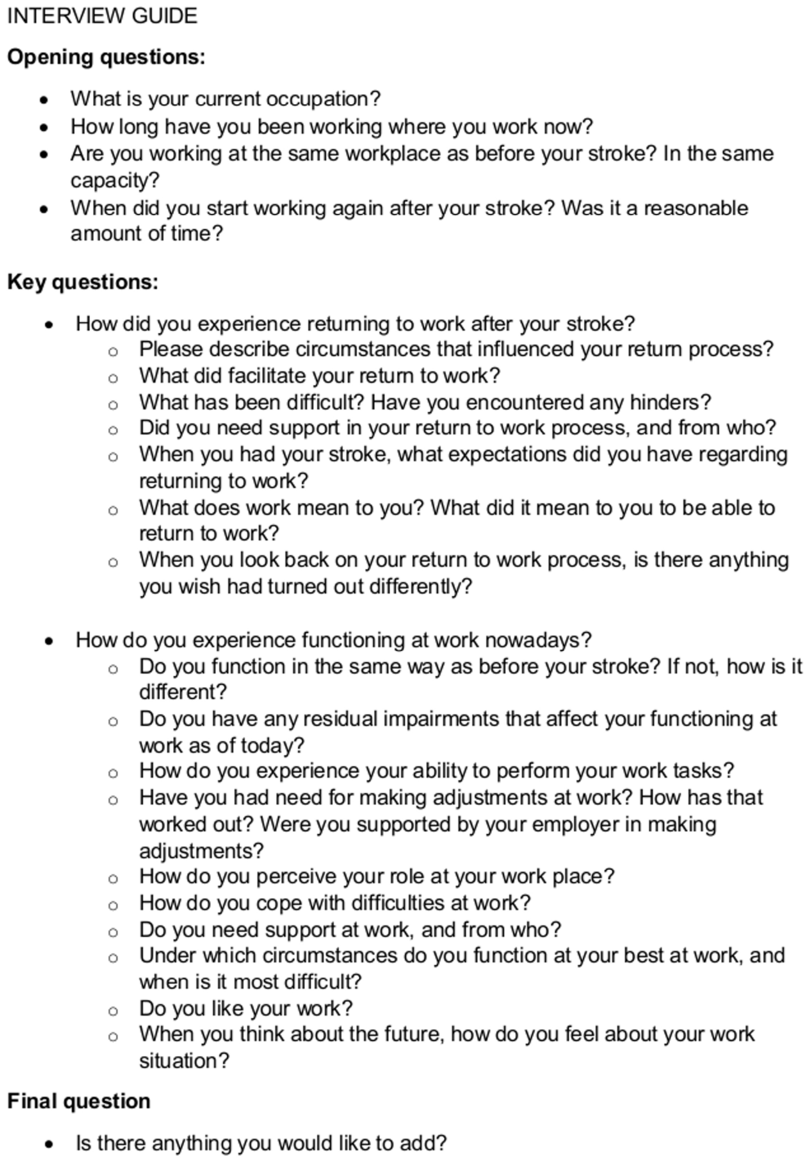
25 Donker-Cools BH, Daams JG, Wind H, et al. Effective return-to-work interventions after acquired brain injury: A systematic review. *Brain Inj* 2016;30(2):113-31.

26 Hinkle JL, Becker KJ, Kim JS, et al. Poststroke Fatigue: Emerging Evidence and Approaches to Management: A Scientific Statement for Healthcare Professionals From the American Heart Association. *Stroke* 2017;48(7):e159-e70.

Figure legends

Figure 1. The interview guide.

Figure 2. The themes and sub-themes developed in the analysis.



INTERVIEW GUIDE

Opening questions:

- What is your current occupation?
- How long have you been working where you work now?
- Are you working at the same workplace as before your stroke? In the same capacity?
- When did you start working again after your stroke? Was it a reasonable amount of time?

Key questions:

- How did you experience returning to work after your stroke?
    - Please describe circumstances that influenced your return process?
    - What did facilitate your return to work?
    - What has been difficult? Have you encountered any hinders?
    - Did you need support in your return to work process, and from who?
    - When you had your stroke, what expectations did you have regarding returning to work?
    - What does work mean to you? What did it mean to you to be able to return to work?
    - When you look back on your return to work process, is there anything you wish had turned out differently?

- How do you experience functioning at work nowadays?
    - Do you function in the same way as before your stroke? If not, how is it different?
    - Do you have any residual impairments that affect your functioning at work as of today?
    - How do you experience your ability to perform your work tasks?
    - Have you had need for making adjustments at work? How has that worked out? Were you supported by your employer in making adjustments?
    - How do you perceive your role at your work place?
    - How do you cope with difficulties at work?
    - Do you need support at work, and from who?
    - Under which circumstances do you function at your best at work, and when is it most difficult?
    - Do you like your work?
    - When you think about the future, how do you feel about your work situation?

Final question

- Is there anything you would like to add?

Figure 1. The interview guide.

106x142mm (600 x 600 DPI)

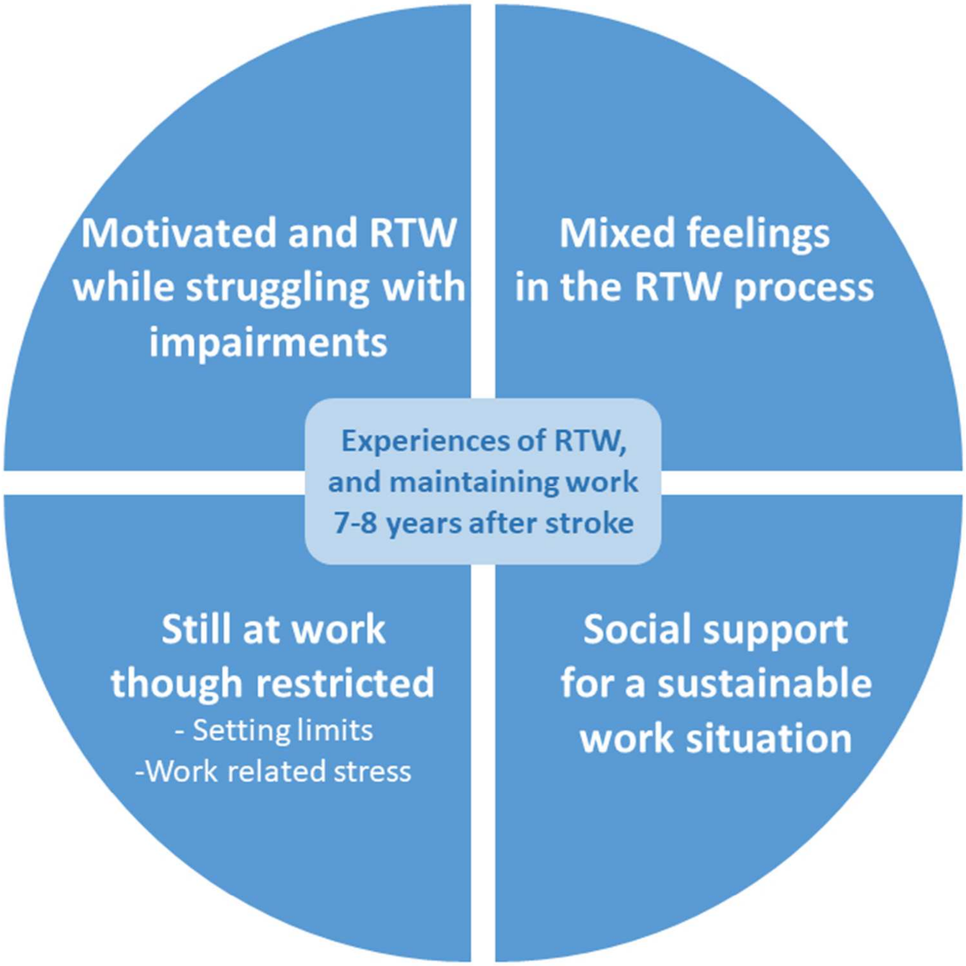


Figure 2. Themes and sub-themes developed in the analysis.

59x60mm (300 x 300 DPI)

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	7
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	7
Occupation	3	What was their occupation at the time of the study?	7
Gender	4	Was the researcher male or female?	7
Experience and training	5	What experience or training did the researcher have?	7
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	5 and 7
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	5
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	5 and 7
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	5
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	5
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	5
Sample size	12	How many participants were in the study?	5
Non-participation	13	How many people refused to participate or dropped out? Reasons?	5
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	7
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	7
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	5-7
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	7 and figure 1
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	n.a.
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	7
Field notes	20	Were field notes made during and/or after the inter view or focus group?	7
Duration	21	What was the duration of the inter views or focus group?	7
Data saturation	22	Was data saturation discussed?	7
Transcripts returned	23	Were transcripts returned to participants for comment and/or	8

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	8
Description of the coding tree	25	Did authors provide a description of the coding tree?	8
Derivation of themes	26	Were themes identified in advance or derived from the data?	8
Software	27	What software, if applicable, was used to manage the data?	n.a.
Participant checking	28	Did participants provide feedback on the findings?	8
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	10, 12-14
Data and findings consistent	30	Was there consistency between the data presented and the findings?	9-14
Clarity of major themes	31	Were major themes clearly presented in the findings?	9 (fig 2), 9-14
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	9 (fig 2), 9-14

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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Experiences of returning to work, and maintaining work 7 to 8 years after stroke in Sweden - a qualitative interview study

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Experiences of returning to work, and maintaining work 7 to 8 years after stroke in Sweden - a qualitative interview study

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Experiences of returning to work, and maintaining work 7 to 8 years after stroke in Sweden - a qualitative interview study

ABSTRACT

Objective: To explore how persons experienced return to work (RTW) and their work situation 7 to 8 years after stroke.

Design: An explorative qualitative design with individual interviews. The data analysis was inductive thematic and three researchers cooperated during the analysis process.

Participants: The study population included five women and eight men who had a stroke during 2009-2010, received care at the Sahlgrenska University Hospital in Gothenburg, Sweden, and RTW after stroke, a heterogenic sample based on age, occupation, stroke severity, and time to RTW.

Results: The analysis led to four themes; *motivated and RTW while struggling with symptoms*, *mixed feelings in the RTW process, still at work although restricted, and social support for a sustainable work situation.* The themes revealed that participants were motivated to RTW while struggling with impairments. The RTW process evoked mixed feelings of worry and grief over lost functions but also acceptance and gratitude for being able to work. Although maintaining work 7 to 8 years after stroke, most were restricted in some way. Fatigue and cognitive impairments meant having to set limits, omit work tasks, and rest at work, but also rest during free time and omit social activities in order to manage work. Participants avoided work related stress if they could because of aggravated symptoms and/or fear of a new stroke. Support from supervisors and colleagues was often crucial for a sustainable work situation.

Conclusion Maintaining work can be a continuous struggle with invisible impairments many years after stroke. Strategies for managing work are dependent on each individual work situation, where support and understanding at work seem to be crucial for a sustainable work situation.

Strengths and limitations of this study (bullet points)

- The focus of this study was the perspective of persons who had worked for years since their stroke, but apart from having this in common, they represented a wide range of occupations, stroke characteristics, and social backgrounds, gave rich interviews and contributed with experiences of maintaining work life after stroke.
- The patient perspective was integrated throughout the study as the interview guide was developed in cooperation with a patient representative from the Swedish Stroke Association, with whom a pilot interview was conducted, and further in the analysis process

the participants were invited to a meeting to discuss and give feedback on the results (participant checking), which gave credibility to the interpretations.

- A limitation of this study was that it only considered the perspective of persons who had RTW after stroke, and not included other stakeholders in the RTW process.
- This study was performed in the Swedish context and the transferability of results to other cultural contexts needs consideration.

INTRODUCTION

Return to work (RTW) is commonly referred to as the event when resuming work after a period of sick leave although a broader view has been suggested to include the whole RTW process, from initial work disability to reaching ones' full potential at work.[1] In Sweden, 25-30 000 people suffer a stroke each year, of whom 20% are of working age, an age group in which stroke has become more common in recent years.[2] The reported RTW rate between one to three years after stroke varies globally between 50 to 74 percent,[3-7] of which two Swedish studies found a RTW rate of 74%.[6, 7] In Sweden, employers have the most explicit responsibility of rehabilitation concerning their employees´ RTW, although shared with health care, the Social Insurance Office (SIO) and the Employment Agency (EA). Employers are obliged to adapt work tasks, working hours, start work trials, and make technical adjustments, though they are not forced to expand or create new work tasks. Common predictors for RTW in people with non-communicable diseases have been found to be higher socioeconomic status, higher self-efficacy, and positive expectations of recovery, less severe illness, better RTW coordination, and multidisciplinary interventions including the workplace.[8] For stroke, less severe stroke and good self-rated health have been reported to be predictors for RTW.[4] Predictors for no RTW have been reported to be physical dependency at discharge,[7] degree of residual disability,[9] sick leave-,[7] or unemployment,[10] prior to stroke, low socioeconomic status,[6] being an immigrant,[10] comorbidities,[10] older age,[5] and being female.[3]

A recent meta-synthesis of qualitative studies on RTW after stroke summarized important factors relative to RTW such as those related to rehabilitation services (availability, accessibility, and appropriateness), the person (impairments, coping, adaptation, and motivation), and the workplace (demands, adaptations, disability management, work climate, and social support).[11] Another qualitative study found that awareness of invisible impairments generated support from employers and colleagues at work and a positive work experience, whereas the opposite presented a large barrier for RTW.[12] A qualitative study suggested the importance of a coordinator for communicating information between stakeholders in the RTW process.[13] Work has been found to be of importance for well-being and life satisfaction after stroke,[14] and RTW can be seen as a strive for normality.[12] Although many studies have investigated factors influencing return or no return to work after stroke, few have studied experiences of working in the long run after stroke.

The aim of this study was to explore experiences of returning to work and maintaining work seven to eight years after stroke.

METHODS

Study design

This is an explorative qualitative study using individual interviews and inductive thematic analysis, which can be referred to a realist/essentialist paradigm.[15] The COREQ guidelines for reporting qualitative research were used.[16] The study was approved by the Regional Ethics Committee in Gothenburg, Sweden, on June 5th 2013 (Dnr: 400-13). Oral and written information was given and written informed consent was received.

Patient and Public involvement

The research question was developed with the aim of learning more about the experiences of persons who had returned to work after having had a stroke. A patient representative from the Swedish Stroke Association was involved in the development and pilot testing of the interview guide. Patients were involved in the conduct of the study, in individual interviews and when invited to a meeting to hear the results and to discuss the interpretation with the authors. The preliminary results of the analysis have been delivered to the study participants in a written letter.

Participants

Participants were identified in the Extended Stroke Arm Longitudinal study at the University of Gothenburg, SALGOT-extended. The inclusion criteria were; having suffered an ischemic or hemorrhagic stroke in the years 2009-2010, having received care at the Sahlgrenska University Hospital in Gothenburg, Sweden, residing in the Gothenburg urban area, being of working age (18-64), and having RTW after stroke. Eighty-two persons were potentially eligible and a letter including information about the purpose of the study, brief information about the clinical and research experience of the interviewer (AP) and information about the research team, was sent out to a purposive sample of 37 persons to achieve a heterogeneous study population based on age, gender, occupation, stroke severity (NIH Stroke Scale (0-46)), and time to RTW. The letter was followed up by a telephone call by AP to confirm participation and to schedule interviews. If a person was not reached by telephone, another letter was sent out encouraging the person to make contact if they were interested in participating. Fourteen persons agreed to participate, but one was excluded due to not having RTW after stroke. The participants were asked to complete a form about demographics and employment. This is presented in Table 1 together with data retrieved from medical charts.

Table 1. Demographic and clinical characteristics of the study population

	Study population (n=13)
Age, mean years (min-max)	50 (39-64)

Gender: Female/Male	 5/8
Country of birth: Sweden Middle East or African country	 10 3
Current living conditions: Living alone Living with partner/ -and children	 5 3/5
Type of stroke: Ischemic stroke Intracerebral hemorrhage	 9 4
Stroke severity (NIH Stroke Scale): Mild (0-4) Moderate (5-15) Severe (16-46)	 10 2 1
Stroke localization: Right hemisphere Left hemisphere Bilateral Not specified	 4 3 1 5
Discharged from stroke unit: Discharged home/ to rehab center	 9/4
Education: ≤ 9 years 10-12 years > 12 years	 5 3 5
Occupations:	Accountant Assistant nurse Civil Engineer Cleaner (n=2) Commander on ferry Dentist Economist Police inspector Production worker Service technician Terminal worker Vehicle fitter
Work related characteristics:	
Time to RTW (period of full time sick leave)	Range: 2 months – 2 years
Same employer as before stroke Lost job before RTW Lost job after RTW	11 1 1

Percent of employment at the time of the interview: 100% 75% 50%	 10 2 1
Employment: Employed in public sector Employed in private sector Self-employed Employed in sheltered work	 5 5 1 2

Data collection

Individual, face-to-face interviews were conducted by the first author (AP) who has a PhD in medicine, is a registered physiotherapist, has previous experience in performing qualitative studies, with no previous relation to the participants, and is a woman with interest in work ability. A semi-structured interview guide with open-ended questions was used and is presented in Figure 1.The interview guide was discussed and revised in cooperation with a patient representative from the Swedish Stroke Association with whom it was first tested in a pilot interview. Thirteen interviews were performed during April to September 2017, three took place in the participants' homes and ten at the rehabilitation medicine research unit facilities. By request of one participant, the interview was conducted in the presence of a next of kin who clarified answers due to language difficulties. The duration of interviews ranged from 40 to 90 minutes. All interviews were audio-recorded and transcribed verbatim by the first author (AP). No field notes were taken during the interviews. After 13 interviews, no new relevant knowledge was being obtained from new participants and hence, data saturation was considered to be achieved.[16]

Insert figure 1 about here

Data analysis

The transcribed interviews were analyzed by inductive thematic analysis[15] as described in Table 2.

Table 2. The steps of thematic analysis according to Braun and Clarke.[15]

Steps	Description
1	Familiarization with data: transcribing, reading, re-reading, noting down initial ideas
2	Generating initial codes: coding interesting features across the entire data set
3	Searching for themes: collecting codes into potential themes, gathering all data relevant to each potential theme

4	Reviewing themes: checking if the themes work in relation to the coded extracts and the entire data set, generating a thematic map of the analysis
5	Defining and naming themes: ongoing analysis to refine the specifics of each theme
6	Producing the report: the final opportunity for analysis, selection of vivid, compelling extract examples, relating back of the analysis to the research question and literature, producing a report of the analysis

First, the transcribed interviews were read and re-read by two of the authors (AP and MT). MT has a PhD (the first social worker with a PhD at the medical faculty) and more than 30 years of experience as a social worker and with qualitative research methodology. The interviews were read separately by the two authors to familiarize with the text and to obtain a sense of the whole. In this process, initial codes were noted separately by the two authors. Second, the authors coded the interviews together and searched for potential themes. The themes were then reviewed and refined by all three authors together and differences were discussed until consensus was reached, with the aim of enhancing the credibility of the analysis. The third author (KSS) is a MD, stroke specialist and Professor in Rehabilitation Medicine with more than 25 years of clinical and research experience in neurological diagnoses. KSS contributed with stroke specific knowledge in discussions concerning revising and refining the themes. The analysis process moved continuously back and forth between the whole and parts of the text to ensure the validity of the themes in relation to the data set. The study participants were invited to a meeting to hear the results and to discuss the interpretation with the authors. Examples of the coding process are provided in Table 3.

Table 3. Examples illustrating the coding tree

Data extract	Code	Theme
(my boss says) “I see that you are tired, you need to rest. You need a break. Sit down there in the corner in my recliner and rest, I can see it in your eyes that you need a break, so I’m ‘shutting you down’ (like a machine) a little and I’ll keep working.”	Acknowledging symptoms and encouraging rest at work	Social support for a sustainable work situation
“they warned me that I’d be fatigued and stuff like that, but I thought I could handle it quite well with the gradual steps that I took. And there were planned rest days… And then the doctor said: people manage to start working pretty well, but it’s important that you have longer recovery times, that are not broken up.”	Experience of RTW at just the right pace	Motivated and returned to work while struggling with impairments

RESULTS

Four themes were identified; *motivated and RTW while struggling with impairments*, *mixed feelings in the RTW process*, *still at work though restricted* which includes two sub-themes, and *social support for a sustainable work situation* (Fig 2). The themes are illustrated with quotes from the participants.

Insert figure 2 about here

Motivated and returned to work while struggling with impairments

Participants described a wide range of impairments that initially affected RTW (Table 4).

Full time sick leave was prescribed for all participants and lasted from two months up to two years. Motivational factors for returning to work were an urge to leave the role of sick person behind, regaining a meaningful daily activity, strong work morals and work identity, economic needs, and a strive for normality.

" The best rehabilitation for me has been starting to work again and getting away from the being sick part, and I wanted to get out and, like, meet people…. It was a way to start to function normally again." Man, 39 years

All participants returned to work gradually in an individually adjusted pace and all but one returned to their previous job, who found a new full-time job. The RTW was sometimes too early or the gradual escalation was sometimes too rapid. This was related to high ambitions in combination with impairments and resulted in setbacks, such as fatigue and emotional stress, which forced a backwards step in the RTW process. This was frustrating, but manageable when focusing on striving forwards in the RTW process. Experiences of RTW at just the right pace or later than appropriate were also reported. They were hindered by doctors, work supervisors, or family members, raising feelings of disappointment or discouragement, but also feelings of being cared for.

"they warned me that I'd be fatigued and stuff like that, but I thought I could handle it quite well with the gradual steps that I took. And there were planned rest days… And then the doctor said: people manage to start working pretty well, but it's important that you have longer recovery times, that are not broken up." Man, 58 years

In the RTW process, individual adaptations of work time, work tasks, and the work environment were performed in partnership with the employer.

"He (my boss) has given me a good room and good nurses and good support, so like, a lot of stuff around me, he has been up for making sure I have calm surroundings and a stable room and not need to change between a bunch of different nurses, I have the same ones, so he's been very supportive in that way…" Woman, 57 years

Work demands were adjusted by refraining from works tasks and responsibilities. Some described no need for adaptations and were content with their work demands.

Table 4. Impairments affecting work initially in the RTW process and 7-8 years after stroke, as expressed by participants.

Initial impairments	**Residual impairments**
Altered mental functions	
Disorientation in time	
Disorientation in space	
Lack of initiative	
Difficulties concentrating	Difficulties concentrating
Difficulties multitasking	Difficulties multitasking
Difficulties processing information and impressions	Difficulties processing information and impressions
Difficulties with numbers and letters	
Memory difficulties	
Depression	
Fatigue	Fatigue
Altered sensory functions and pain	
Sensitivity to sound	
Sensory loss and alterations	
Headache	Headache
Balance difficulties	Vertigo and balance difficulties
Altered neuromusculoskeletal functions	
Muscle weakness on one side of the body	Muscle weakness on one side of the body
Coordination difficulties	
Altered voice and speech functions	
Losing volume of voice	

Mixed feelings in the RTW process

Uncertainty about consequences of stroke and prognosis of recovery raised worries about the future, including work life. Speculations about whether impairments were age- or stroke-related were expressed. Expectations of a fast recovery sometimes led to disappointment later when still struggling with impairments, or to satisfaction when the recovery rate turned out as expected. Some had been told by doctors that they would fully recover but when still struggling with impairments and work tasks 7-8 years after stroke they wondered how and when that would happen. However, gratitude for functioning well despite stroke when considering how life might have turned out was expressed; they had been given a second chance in life and could work.

"I'm happy to be able to work 75%, because I had a large stroke, so the idea that I'm able to work at all, that's completely amazing." Woman, 57 years

Acceptance of impaired functions as well as a more relaxed attitude towards work life were expressed. Participants described satisfaction with regained functions, but also frustration and grief over lost functions and disappointment at having been deprived of career opportunities.

Still at work though restricted

Seven to eight years after stroke, impairments were less obvious than initially post stroke, though most participants had impairments that still interfered with work (Table 4).

Setting limits

Setting limits for colleagues, patients, and customers to create opportunities for rest and undisturbed work was one strategy used to manage work demands. It was hard, and time consuming to shift focus and get back on track with their own work tasks after being disrupted by others, forcing participants to set limits for interaction with colleagues in order to focus on their own tasks. Limiting ambition was a way to avoid fatigue, this could mean delegating work tasks or accepting a more subordinate work role. When demands on multitasking and information processing were too high, this could lead to confusion, insecurity, and refraining from work tasks. Difficulties setting limits at work were experienced when expressed needs were not heard by supervisors or colleagues. Sometimes, participants chose not to participate in social activities at work due to fatigue, forced to focus on work tasks and nothing else.

"Some days are a lot, and you get interrupted the whole time during your breaks and stuff…though I try and work around that by not going on break when everyone else does. Sometimes I've thought that my brain needs to rest a little, it's fun to sit and chat with the others so I'm part of the group, but some days I feel… I want to take the opportunity to have a break when the others have gone so I can have a little bit of peace." Woman, 48 years

When trying to keep up appearances to compete with colleagues, one participant avoided setting limits. However, some found it easier to set limits now than before their stroke, they mentioned being able to stand up for themselves and knowing more about their rights.

Independent work was described to allow for work at their own pace, providing opportunities to prepare and plan work according to their own functional level. Fatigue was described as a dominant impairment that was coped with by taking pauses at work, which was allowed for at some workplaces but not at others.

“then there’s the fatigue, if I’m going to have a more complicated meeting with a customer, or if I need to have a wage renegotiation meeting or performance review, I always have them in the morning. I always plan them for the mornings, because in the afternoon I get more fatigued, unfortunately.” Woman, 45 years

Gaining insight post stroke into the importance of taking care of their own health sometimes led to prioritizing physical exercise in order to be able to function better at work. But finding the energy for exercise was sometimes impossible when they were stuck in the vicious circle of fatigue and work demands. Some described exercising less than before the stroke, due to the fear of a new stroke. Participants described an excessive need for rest, before and after work. Spare time activities were often neglected due to lack of energy and were replaced by rest and sleep to manage work.

“Before I had my stroke I had an allotment, so when I was finished at work I’d go and dig and do some work there. I rode my bike there. Now I just can’t manage it… I feel that things are different to before, but I want to live like that, like, I don’t want to push the limits, I want to try and live the way I am able to.” Man, 59 years

Work related stress

Work demands of being constantly available to customers, patients, or colleagues and a competitive work environment, lack of control of workload, and irregular inflow of work created stress. Also, having to adjust to changing work schedules, being forced to work overtime, or having to manage the same work demands as before stroke were stressful.

When exposed to stress at work, participants described having symptoms like the ones they had at stroke onset, such as sensations of numbness, tingling, and headache, which gave rise to the fear of having a new stroke.

“So every time you get a headache you start to think negatively, think if it’s another thing like that that is happening (a new stroke) … before I had the stroke, you could say I was very stressed out. But

now I don't stress as much. I think, nah it will take the time it takes and not stress too much, it's just that way. So, like at work right now, you work but not as intensively as you did before, and you have to think about your own health too." Man, 46 years

The participants tried to avoid work related stress but when this proved impossible, one started his own business to regain control over his workload. Others were forced to stress at work and endured recurrent symptoms such as headache, fatigue, vertigo, or high blood pressure and felt trapped because of economic needs or were too exhausted to change jobs.

Social support for a sustainable work situation

Participants felt looked after and privileged when supported by their supervisor. A supervisor could advocate work task adaptations, acknowledge symptoms, and encourage rest at work, or could accept flexible working hours.

(my boss says) "I see that you are tired, you need to rest. You need a break. Sit down there in the corner in my recliner and rest, I can see it in your eyes that you need a break, so I'm 'shutting you down' (like a machine) a little and I'll keep working." Woman, 48 years

Some participants did not feel supported by their supervisor, who ignored them and their needs which created a strenuous work situation. One supervisor gave mixed signals, both being supportive and setting unreasonable demands at the same time. One participant had been discouraged by the supervisor at a rehabilitation meeting but stood up against the supervisor and gained support that way. One participant felt actively discouraged by the supervisor and experienced that the supervisor tried to force them to resign.

"And she, my boss, doesn't accept the doctor's certificate but it's, I don't know what to say, they're against me…In two weeks I'm going to work nights, but I…they want me to take the week off unpaid. Last time it was a late shift I took holiday leave…" Man, 59 years

Participants said that it felt safe to return to the same work team, they got along well with colleagues when they could communicate openly and joke about their symptoms at work. When impairments did not interfere with work, some appreciated being treated like anyone else, but when impairments affected work, some appreciated to be relieved of work tasks, and receive social support from colleagues.

Societal support could mean assistance from a labor union, the Swedish Social Insurance Agency, or the Employment Agency in the RTW process. One could feel supported but also exposed by contact with these authorities.

DISCUSSION

Findings

The analysis led to four themes revealing that participants were motivated to RTW while struggling with impairments in the RTW process. The RTW process evoked mixed feelings of worry and grief over lost functions but also acceptance and gratitude for being able to work. Although maintaining work 7-8 years after stroke, most were restricted in some way. Fatigue and cognitive impairments meant having to set limits, omit work tasks, and rest at work but also rest during spare time and omit social activities to manage work life. Participants avoided work related stress if they could because of aggravated symptoms and/or fear of a new stroke. Support from supervisors and colleagues was often crucial for a sustainable work situation, but when not supported or even discouraged at work, it could mean a lonesome struggle enduring impairments and stress related symptoms while pushing their limits to manage work demands.

Strengths and limitations

A strength of this study was that the interview guide was developed in cooperation with a patient representative from the Swedish Stroke Association with whom a pilot interview was conducted. Another strength was the heterogeneity of the study population, representing a wide range of occupations, stroke characteristics, and social backgrounds. The participants gave rich interviews and contributed with a wide range of experiences. In the analysis process, two authors with different professional backgrounds (medical social worker and physiotherapist) coded separately and then jointly, ensuring a thorough coding process with the aim of capturing all relevant data. When developing, revising, and refining themes, open discussions involving all three authors on coherency, consistency, and distinctiveness led to consensus which contributed to the credibility of the study.[15] When invited to a meeting (participant checking), participants gave feedback on the results which were taken into account and gave further credibility to the interpretations. A limitation of this study was that it only considered the perspective of persons who had RTW after stroke, and not included other stakeholders in the RTW process. Also, this study was performed in the Swedish context and the transferability of results to other cultural contexts needs consideration.

Comparison with existing literature and guidelines

In this study, we gained a profound perspective of RTW from the view of persons with stroke who had managed to RTW and stay at work for many years. Work seemed to be important to the participants, who were all motivated to RTW. This can be interpreted in the light of previous findings stating work as an important part of life, identity, and social context.[17] Being motivated to RTW has also been found to be a facilitator for RTW after stroke from an employer perspective.[18] However, high ambitions in the RTW process could generate setbacks, as shown in this study.

Disagreements with doctors, employers, or family members could be a concern when readiness for RTW is uncertain which has also previously been reported.[19] The importance of achieving appropriate, gradual RTW in combination with formal adjustments provided by the employer needs to be addressed, as previously suggested.[11]

Although having successfully RTW and still working 7-8 years after stroke, life was often restricted for participants in this study. Setting limits at work, omitting leisure- and social activities to meet an excessive need for rest, as well as trying to avoid work related stress were central strategies used to manage work life, in line with previous findings.[12] Consequently, this could mean prioritizing work and rest, having no spare energy for other life activities. On the other hand, having gained a more relaxed approach to work after stroke, some participants prioritized wellbeing and leisure activities and were content with a less senior work role or with working part-time when possible. The importance of work for wellbeing and life satisfaction after stroke has been emphasized.[14] We argue that maintaining work could be a continuous struggle many years after stroke and the use and success of coping strategies are dependent on each individual work situation, where the question of support from employers has a great impact on working conditions.

Some felt supported by their employer and others did not, maintaining work life at the expense of their own wellbeing, which could lead to the risk of future resignation, as previously presented.[12] Receiving no support from their employer could be related to difficulties in communicating impairments and adjustment needs, in particular when impairments were invisible, such as cognitive difficulties and fatigue. This could be a concern for managing work in the long run, as hidden impairments acting as key barriers for RTW has previously been suggested.[11] Employers' lack of medical knowledge, especially regarding cognitive impairments, could restrict them in making adequate adjustments.[13] Apart from gaining stroke specific knowledge from their employee, employers have used the internet as their primary source of information.[18] Thus, the communication of impairments and needs for adjustments to the employer seems crucial for receiving the support needed in the RTW process. To facilitate this communication, a stroke coordinator, who would support patients and stakeholders during the RTW process, has been suggested by other researchers.[13, 20]

Clinical and policy implications

In this study, most participants had a mild stroke and were discharged from the hospital directly to their homes. Nevertheless, most still experienced cognitive impairments and fatigue that interfered with work life many years later. Cognitive impairments persisting for many years after stroke, also in people with mild stroke, have been presented previously.[21] Further, cognitive function has been found to predict RTW in people with mild to moderate stroke,[22] and although returning to work,

people with mild stroke have been reported not to be able to perform their jobs as previously due to cognitive impairments.[23] However, cognitive rehabilitation interventions have focused little on this group.[22, 24] In relation to this and the findings of our study, we suggest that more attention should be given to rehabilitation of the invisible cognitive impairments experienced by people with mild to moderate stroke in the RTW process. However, a systematic review of RTW interventions found the evidence of effectiveness of cognitive rehabilitation by itself or along with work-directed interventions to be low for people with acquired brain injury.[25]

Based on the results of our study and previous findings, the strategies used to cope with invisible impairments in the RTW process after stroke seem to be essential.[11, 12] Development of strategies such as balancing activity and rest, setting limits, and avoiding work related stress could be supported by stroke rehabilitation teams. However, interventions for managing fatigue after stroke have insufficient evidence.[26]

It seems important to encourage patients to contact their workplace early in order to facilitate communication about their individual impairments and needs in the RTW process, to receive adjustments and social support from their employer. Rehabilitation meetings with the patient and involved stakeholders could be a forum for such information sharing. In line with our suggestion, there is strong evidence for the effect of interventions including a combination of work-directed components and education/coaching on RTW.[25]

Future research

Investigating aspects of work life many years after stroke, quantitative studies or studies using mixed methods to combine patient perspectives with quantitative data on work stability, cognitive impairments, and fatigue would add generalizable knowledge.

Randomized controlled trials focusing on strategies to cope with, and communicate cognitive impairments and fatigue in the RTW process for persons with mild to moderate stroke are called for. Interventions could be based on strategies for managing work life after stroke as presented in this study.

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Author contribution

AP, MT, and KSS contributed to the design of the study. AP conducted and transcribed the interviews and analyzed the data together with MT, involving KSS in the final stages of analysis. AP and MT wrote the first version of the manuscript, which was reviewed by KSS. All three authors contributed to and approved the final manuscript.

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Competing interests

None declared.

Data sharing

Due to ethical restrictions, data are available upon request. Interested researchers may submit requests for data to the authors (contact: ks.sunnerhagen@neuro.gu.se). Complete interview data cannot be made publicly available for ethical and legal reasons, according to the Swedish regulations http://www.epn.se/en/start/regulations/. Public availability would compromise participant confidentiality or privacy. Upon request a list of condensed meaning units or codes can be made available after removal of details that may risk the confidentiality of the participants. To access such data please contact the first author: (annie.palstam@gu.se).

REFERENCES

1 Young AE, Roessler RT, Wasiak R, et al. A developmental conceptualization of return to work. *Journal of occupational rehabilitation* 2005;15(4):557-68.DOI:10.1007/s10926-005-8034-z.

2 Riksstroke (the Swedish Stroke Resister). Yearly report (Acute-, TIA- and 3 month follow-up). 2015. Available from: www.riksstroke.org/wp-content/uploads/2015/12/Strokerapport_AKUT-TIA_LR.pdf.

3 Hannerz H, Holbaek Pedersen B, Poulsen OM, et al. A nationwide prospective cohort study on return to gainful occupation after stroke in Denmark 1996-2006. *BMJ Open* 2011;1(2):e000180.DOI:10.1136/bmjopen-2011-000180.

4 Larsen LP, Biering K, Johnsen SP, et al. Self-rated health and return to work after first-time stroke. *J Rehabil Med* 2016;48(4):339-45.DOI:10.2340/16501977-2061.

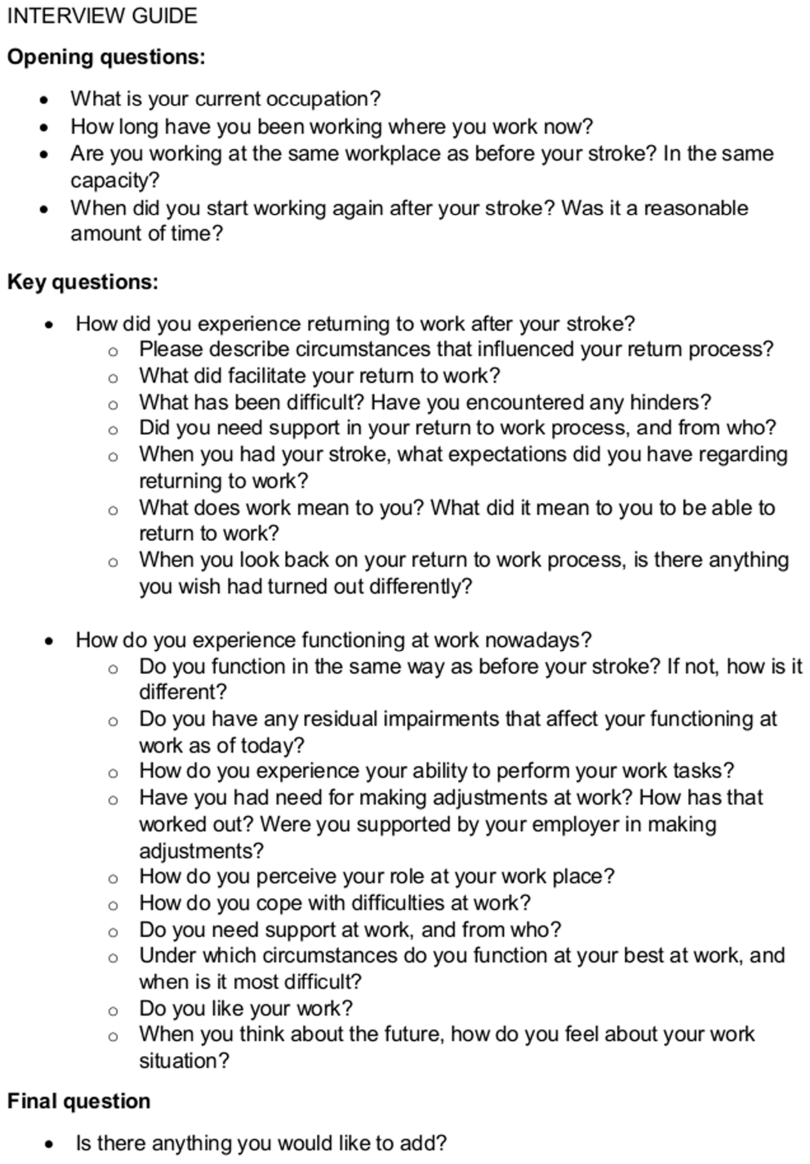
5 Endo M, Sairenchi T, Kojimahara N, et al. Sickness absence and return to work among Japanese stroke survivors: a 365-day cohort study. *BMJ Open* 2016;6(1):e009682.DOI:10.1136/bmjopen-2015-009682.
6 Glader EL, Jonsson B, Norrving B, et al. Socioeconomic factors' effect on return to work after first stroke. *Acta neurologica Scandinavica* 2017;135(6):608-13.DOI:10.1111/ane.12639.
7 Westerlind E, Persson HC, Sunnerhagen KS. Return to Work after a Stroke in Working Age Persons; A Six-Year Follow Up. *PLoS One* 2017;12(1):e0169759.DOI:10.1371/journal.pone.0169759.
8 Cancelliere C, Donovan J, Stochkendahl MJ, et al. Factors affecting return to work after injury or illness: best evidence synthesis of systematic reviews. *Chiropractic & manual therapies* 2016;24(1):32. DOI:10.1186/s12998-016-0113-.
9 Wang YC, Kapellusch J, Garg A. Important factors influencing the return to work after stroke. *Work (Reading, Mass)* 2014;47(4):553-9.DOI:10.3233/wor-131627.
10 Virtanen M, Ervasti J, Mittendorfer-Rutz E, et al. Work disability before and after a major cardiovascular event: a ten-year study using nationwide medical and insurance registers. *Scientific reports* 2017;7(1):1142.DOI:10.1038/s41598-017-01216-2.
11 Schwarz B, Claros-Salinas D, Streibelt M. Meta-Synthesis of Qualitative Research on Facilitators and Barriers of Return to Work After Stroke. *J Occup Rehabil* 2017.DOI:10.1007/s10926-017-9713-2.
12 Balasooriya-Smeekens C, Bateman A, Mant J, et al. Barriers and facilitators to staying in work after stroke: insight from an online forum. *BMJ Open* 2016;6(4):e009974.DOI:10.1136/bmjopen-2015-009974.
13 Hellman T, Bergstrom A, Eriksson G, et al. Return to work after stroke: Important aspects shared and contrasted by five stakeholder groups. *Work (Reading, Mass)* 2016;55(4):901-11.DOI:10.3233/wor-162455.
14 Vestling M, Tufvesson B, Iwarsson S. Indicators for return to work after stroke and the importance of work for subjective well-being and life satisfaction. *Journal of Rehabilitation Medicine* 2003;35(3):127-31.
15 Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative research in psychology* 2006;3(2):77-101.
16 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care : journal of the International Society for Quality in Health Care* 2007;19(6):349-57.DOI:10.1093/intqhc/mzm042.
17 Christiansen CH. Defining lives: Occupation as identity: An essay on competence, coherence, and the creation of meaning. *American Journal of Occupational Therapy* 1999;53(6):547-58.DOI:10.5014/ajot.53.6.547.
18 Coole C, Radford K, Grant M, et al. Returning to work after stroke: perspectives of employer stakeholders, a qualitative study. *J Occup Rehabil* 2013;23(3):406-18.DOI:10.1007/s10926-012-9401-1.

19 Gilworth G, Phil M, Cert A, et al. Personal experiences of returning to work following stroke: An exploratory study. *Work (Reading, Mass)* 2009;34(1):95-103.DOI:10.3233/wor-2009-0906.
20 Ost Nilsson A, Eriksson G, Johansson U, et al. Experiences of the return to work process after stroke while participating in a person-centred rehabilitation programme. *Scand J Occup Ther* 2017;24(5):349-56.DOI:10.1080/11038128.2016.1249404.
21 Ytterberg C, Dyback M, Bergstrom A, et al. Perceived impact of stroke six years after onset, and changes in impact between one and six years. *J Rehabil Med* 2017;49(8):637-43.DOI:10.2340/16501977-2258.
22 van der Kemp J, Kruithof WJ, Nijboer TC, et al. Return to work after mild-to-moderate stroke: work satisfaction and predictive factors. *Neuropsychological Rehabilitation* 2017:1-16.DOI:10.1080/09602011.2017.1313746.
23 O'Brien AN, Wolf TJ. Determining work outcomes in mild to moderate stroke survivors. *Work (Reading, Mass)* 2010;36(4):441-7.DOI:10.3233/wor-2010-1047.
24 Faux SG, Arora P, Shiner CT, et al. Rehabilitation and education are underutilized for mild stroke and TIA sufferers. *Disabil Rehabil* 2017:1-5.DOI:10.1080/09638288.2017.1295473.
25 Donker-Cools BH, Daams JG, Wind H, et al. Effective return-to-work interventions after acquired brain injury: A systematic review. *Brain Inj* 2016;30(2):113-31.DOI:10.3109/02699052.2015.1090014.
26 Hinkle JL, Becker KJ, Kim JS, et al. Poststroke Fatigue: Emerging Evidence and Approaches to Management: A Scientific Statement for Healthcare Professionals From the American Heart Association. *Stroke* 2017;48(7):e159-e70.DOI:10.1161/str.0000000000000132.

Figure legends

Figure 1. The interview guide.

Figure 2. The themes and sub-themes developed in the analysis.



INTERVIEW GUIDE

Opening questions:

- What is your current occupation?
- How long have you been working where you work now?
- Are you working at the same workplace as before your stroke? In the same capacity?
- When did you start working again after your stroke? Was it a reasonable amount of time?

Key questions:

- How did you experience returning to work after your stroke?
    - Please describe circumstances that influenced your return process?
    - What did facilitate your return to work?
    - What has been difficult? Have you encountered any hinders?
    - Did you need support in your return to work process, and from who?
    - When you had your stroke, what expectations did you have regarding returning to work?
    - What does work mean to you? What did it mean to you to be able to return to work?
    - When you look back on your return to work process, is there anything you wish had turned out differently?

- How do you experience functioning at work nowadays?
    - Do you function in the same way as before your stroke? If not, how is it different?
    - Do you have any residual impairments that affect your functioning at work as of today?
    - How do you experience your ability to perform your work tasks?
    - Have you had need for making adjustments at work? How has that worked out? Were you supported by your employer in making adjustments?
    - How do you perceive your role at your work place?
    - How do you cope with difficulties at work?
    - Do you need support at work, and from who?
    - Under which circumstances do you function at your best at work, and when is it most difficult?
    - Do you like your work?
    - When you think about the future, how do you feel about your work situation?

Final question

- Is there anything you would like to add?

Figure 1. The interview guide.

106x142mm (600 x 600 DPI)

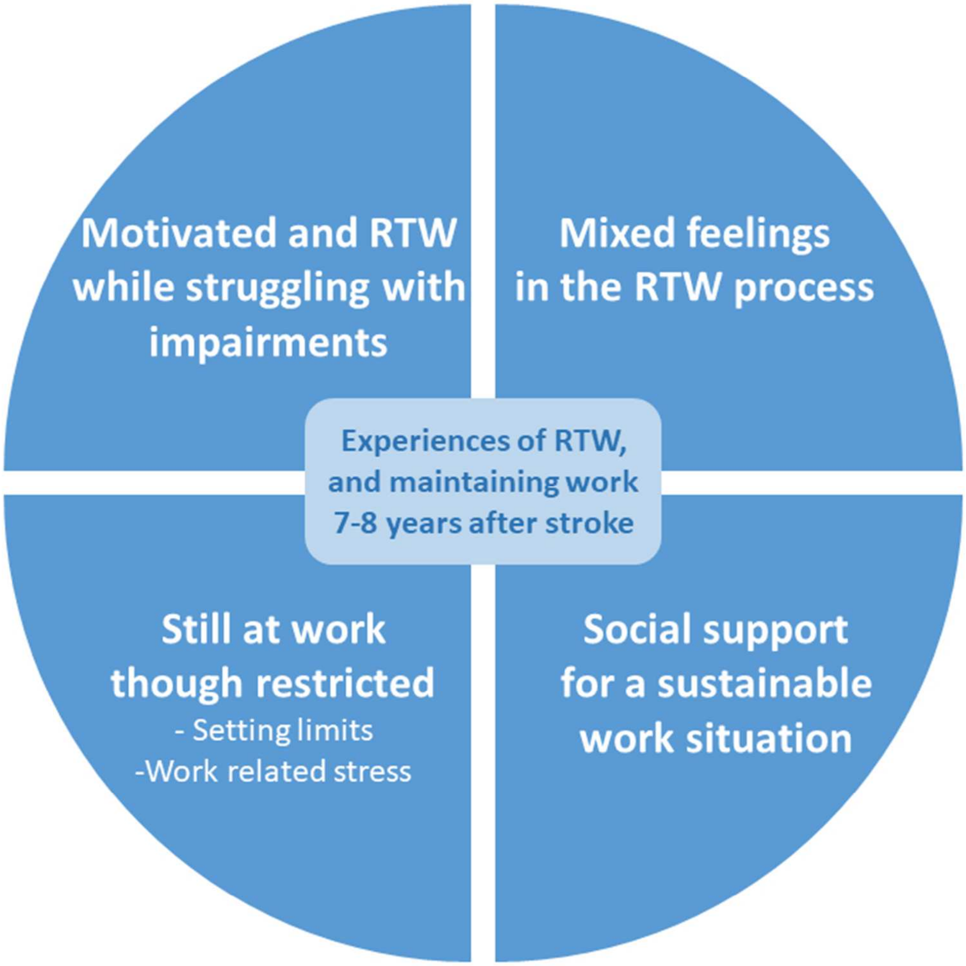


Figure 2. Themes and sub-themes developed in the analysis.

59x60mm (300 x 300 DPI)

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	7
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	7
Occupation	3	What was their occupation at the time of the study?	7
Gender	4	Was the researcher male or female?	7
Experience and training	5	What experience or training did the researcher have?	7
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	5 and 7
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	5
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	5 and 7
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	5
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	5
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	5
Sample size	12	How many participants were in the study?	5
Non-participation	13	How many people refused to participate or dropped out? Reasons?	5
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	7
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	7
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	5-7
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	7 and figure 1
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	n.a.
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	7
Field notes	20	Were field notes made during and/or after the inter view or focus group?	7
Duration	21	What was the duration of the inter views or focus group?	7
Data saturation	22	Was data saturation discussed?	7
Transcripts returned	23	Were transcripts returned to participants for comment and/or	8

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	8
Description of the coding tree	25	Did authors provide a description of the coding tree?	8
Derivation of themes	26	Were themes identified in advance or derived from the data?	8
Software	27	What software, if applicable, was used to manage the data?	n.a.
Participant checking	28	Did participants provide feedback on the findings?	8
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	10, 12-14
Data and findings consistent	30	Was there consistency between the data presented and the findings?	9-14
Clarity of major themes	31	Were major themes clearly presented in the findings?	9 (fig 2), 9-14
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	9 (fig 2), 9-14

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.