How primary care can help stroke survivors with returning to work: focus groups with stakeholders from a UK community

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How this fits in

Many people of working age who have a stroke want to return to work, but encounter difficulties. Existing research does not give us clear cut answers as to how primary care can best enable people with stroke to achieve this. We explored the role of primary care with different stakeholders. This identified a limited current role for GPs; highlighted a mismatch between patient and carer needs and what is provided; and the limited awareness and integration of primary care with other services, in particular neurorehabilitation services whose capacity is limited. Clinical commissioners envisaged problems with commissioning neurorehabilitation services due to lack of evidence of cost-effectiveness. Suggestions for improvement included 1) a dedicated primary care clinician navigating patients through available services. 2) A neurorehabilitation assessment integrated within the primary care electronic record, highlighting invisible impairments. 3) A patient held shared-care plan at discharge from hospital.

Abstract

Background

Evidence about how primary care can best enable stroke survivors going back to work is limited.

Aims

Exploring the role of primary care in supporting TIA/stroke survivors returning to work with stakeholders from a local UK community.

Design

Four focus groups with 18 participants, including TIA/stroke survivors, carers, employer representative, GPs, Occupational Therapists and clinical commissioners.

Methods

Qualitative study using framework analysis.

Results

There was a mismatch between patient and carer needs and what is provided by primary care. This included lack of GP awareness of invisible impairments, uncertainty how primary care could help in time-limited consultations and complexity of return-to-work issues. Primary care physicians were not aware of relevant services they could refer patients to, such as OT support. In addition, there was an overall lack of coordination between different stakeholders in the returning to work process. Linking with other services was considered important but challenging due to ongoing changes in service structure and the commissioning model. Suggestions for improvement include a central contact in primary care for signposting to available services, a rehabilitation assessment integrated with the electronic record, and a patient-held share-care plan at discharge from stroke wards.

Conclusion

Improving the role for primary care in helping stroke survivors returning to work is challenging. However, primary care could play a central role in initiating / coordinating vocational rehabilitation - through focus group discussions with stakeholders from a local community, patients, carers and clinical commissioners were able to put forward concrete proposals to address the barriers identified.

Introduction

A quarter of all strokes happen in working age,[1] with a general practice with list size of 6,000 patients containing on average 15 stroke survivors aged between 18 and 65 years.

Enabling people with stroke to work has positive effects on health[2,3,4] and unemployment is associated with physical and mental health problems.[5,6] It is estimated that stroke costs the UK around £9 billion a year as a society. This includes £1.3 billion in lost income due to care, disability and death, and over £800 million in benefit payments.[3]

The 2007 UK's stroke strategy[7] highlighted the need for stroke survivors to be enabled to participate in paid, supported, and voluntary employment, identifying any obstacles to returning to work in order to develop interventions and build the health economic evidence that would support commissioning of these services. [4,8] The 2013 NICE guidelines on stroke rehabilitation recognise the value of returning to work and mention impairments including psychological difficulties and fatigue.[8]

A systematic review of seventy studies has shown that return to work in post-stroke patients of working age varies from 0 to 100%.[2] Our previous study among a UK online community of patients with stroke and relatives[9] revealed that stroke survivors as well as those who suffered from TIA-only experienced residual invisible impairments, which could affect staying in work. In addition, primary care has a limited role in helping stroke survivors who managed to return to employment to staying in work. In particular, participants described primary healthcare professionals' difficulties recognising the effects of 'invisible' impairments such as fatigue, memory and concentration problems and their long-lasting nature on the ability to work.[10,11]

When brain injury problems persist long-term, guidelines suggest that people should be able to self-refer to appropriate services, though awareness of this recommendation is limited.[11] Occupational health services vary greatly across the UK and between employers.[12] Although the introduction of GP fit notes in 2010 could potentially have had positive effects on staying in work by acknowledging specific limitations of stroke survivors at the workplace, it seemed to have made little impact. One of the explanations for this was that it was perceived as the 'easiest' options for GPs to sign off stroke survivors from work as being 'not fit'.[13] Therefore there is need to explore the current role of primary care in helping stroke and TIA survivors returning to work and how primary care interfaces with other community stakeholders in order to better support employment after stroke.

The objective for this study was to explore the role of Primary Care in supporting TIA/stroke survivors returning to work gathering views from stakeholders in a local community.

Methods

Design

Qualitative study using framework analysis of four focus groups held in Cambridgeshire with TIA/stroke survivors, carers, employer representative, GPs, Occupational Therapists (OTs) and clinical commissioners. Focus groups were chosen to create discussion between stakeholders and create the opportunity to identify difficulties in the returning to work process. We carefully chose the composition of focus groups – the first three groups included patients, carers as well as GPs and OTs. The fourth focus group included professionals involved in employment, return to work care and commissioning of services. We were specifically interested in interaction between stakeholders, however, we chose not to include patients together with employers in order to avoid difficult situations and inhibition of expression.

Participants

Stroke survivors, caregivers and GPs were recruited from two GP practices in Cambridgeshire (one inner city and one village practice), while two additional patients were recruited from the local community neurorehabilitation service. Occupational Therapists were recruited from local community neurorehabilitation service and a specialist neurorehabilitation centre (Oliver Zangwill Centre), clinical commissioners from the local CCG and the employer representative through the University.

Invitation letters to the study were sent out to patients aged 18-65 years on stroke registers. The letter included a freepost envelope and a reply slip to identify physical, communication or cognitive impairments, and degree of returning to work: no return to work, work on voluntary basis, work part time, work full time. Caregivers were invited to attend through the patients. Due to the small sample size of eligible patients,[14] convenience sampling was used.

Data collection

Four focus groups were conducted between September and November 2015. Topic guides were developed from a previous study by the authors[9] and input from researchers with expertise in qualitative methods, primary care, and neurorehabilitation. An experienced researcher in qualitative methods (CBS) and an experienced OT facilitated the focus groups, which included four to twelve participants per group. The topic guides were piloted with a patient group in a specialist neurorehabilitation service (Oliver Zangwill Centre) before data collection.

Three focus groups were held in the practice premises, the first with stroke survivors, caregivers and OTs only, while the second and third were joined by the GP from each participating practice. The fourth focus group was attended by clinical commissioners, OTs and an employer representative and took place at University premises. All focus groups were audiotaped and transcribed by The Typing Works.[15]

Data analysis

CBS and ADS met following each focus group to discuss emerging findings and analytical questions. Although formal coding started after the four focus groups were completed, ADS and CBS discussed content and notes after each FG in preparation of the subsequent one. Framework analysis was used to analyse the transcripts.[16] An initial framework was developed by CBS based on data immersion and initial coding and all data was then mapped onto the framework and summarised (indexed). Data were then interpreted in-depth (CBS and ADS) looking for patterns and relations and by cross-case comparison of initial topics/themes.

Results

Eighteen participants including stroke survivors, carers, OTs, GPs, employer representative and clinical commissioners participated in this study (Table 1). Six stroke survivors and two caregivers were recruited from two GP practices, while two additional patients were recruited from the local vocational rehabilitation service. The analysis resulted in two main themes:

- Mismatch between patient and carer needs, and what is provided. This theme focuses on the relationship between patients with TIA/stroke and primary care.
- Lack of co-ordination/communication between the different agencies involved and primary care. This theme focuses on the relationship between primary care and other agencies involved in returning to work.

For each of these themes, ways of addressing the highlighted issues were discussed in the focus groups. The names reported in quotes are not real names, but have been anonymised.

Mismatch between patient and carer needs, and what is provided

<u>Awareness of invisible impairments</u>

Patients and GPs awareness of hidden stroke impairments were different.

What's very interesting for me listening to all of this [i.e. patients and carers discussions] *as a GP is that as a doctor we have this very sort of black and white view of a stroke I think which is shared I suspect by society and we all think the same way that the stroke is about loss of power and loss of vision and those sorts of things and yet everything that you're saying is about subtle changes, it's about memory, it's about concentration, it's about fatigue which are things that are really hard for other people to recognise and really hard to explain and then perhaps are ignored but seem to be in a sense much more important than the obvious signs of a stroke.(GP1)*

Assessing invisible impairments such as fatigue was also challenging, even for an occupational health doctor, due to lack of a formal tool.

"When I was working on patient medicine you would actually go off what the patient, what the client themselves was saying their ability was at that point. So they would say, "oh well, so how long would you be able to say for instance do your work, up to the point where you would have to take a break? … there's no formal assessment [for fatigue]*…it actually just goes off the patient, off the client's opinion." (CC2).*

<u>Challenges during GP consultations</u>

Although both stroke survivors and clinicians felt that GP support is important, stroke survivors and carers felt major barriers for GPs to play a role in return to employment. Time of consultations was limited. Further, there was the belief that GP consultations were primarily for medical issues, while job-related discussion topics were felt as less appropriate and they were unsure how the GP consultation could help in returning to work.

Well my experience of the GP is exactly the same, I go in, he'll take my blood pressure, look at a blood test, look at the drugs I was on, you know, any issues but I don't know what else I expected from him. (P3)

<u>Returning to work issues are complicated</u>

Planning return to work was considered a difficult task at times by GPs and clinical commissioners.

"It all depends upon stability of the situation to be honest with you and predictability as well because if you're trying to get a patient, trying to get a client back to work and you've not had a period of stability in their condition, it's very hard to actually sort of make any formal plan" (CC2)

GPs described filling sickness or fitness notes challenging and faced the issue of employers coming back to them asking for a sicknote instead of considering work adjustments.

"...and when I, with most employers, when I attempt to write a fit note… trying to make some suggestions about amended duties etc., and most employers I just get a note back usually via the patient going "What? Can you write him a sick note?" (CC1)

Improving the role of primary care: A point of contact for work-related issues

As GPs were considered very busy and mainly focused on the clinical aspects of stroke recovery, having a designated point of contact in primary care clinician to contact for post-stroke work related issues was suggested and was felt important by patients, carers as well as GPs.

"Yeah. I mean you could train a nurse, it doesn't necessarily have to be a GP does it? Nowadays they have specialist asthma nurses who know more about asthma than the GP. So you don't necessarily have to skill up to the extent that you need to know all of the neuro implications but you need somebody who can facilitate the questions and finding the answer and say "okay, I don't know that but I know where to go to" (C1)

However, a concern would be that services are duplicated and even more complex.

"It's an interesting point isn't it, whether by doing that you just duplicate and make things more complicated or whether it actually simplifies things because there are clearly all these other agencies, Citizens Advice, occupational health, all these other people doing similar sorts of things and whether if you provide something within GP practices you're just providing another layer of complexity that's not communicating with anyone else." (GP1)

Clinical commissioners mentioned a pilot ongoing at the time of a software aimed at helping the process of navigating and sign-posting to current services.

"… a decision management software tool which has been purchased, ...we purchased a licence for a pilot number of practices, about twenty odd practices and this is meant to be something that sits on the patients, on the GP's desktop and it gives, and if you put in say stroke it will ping up saying "here are the local services for stroke" (CC2)

Lack of co-ordination/communication between the different agencies involved and primary care

Awareness of services

Despite recognising work is good for patient health, in terms of suggesting community services for helping with returning and staying in work, GPs described difficulties with knowing about all services available and pointing stroke survivors to the right ones. GPs and clinical commissioners were also unaware of the option of direct referral between primary care and community Occupational services, which was thought to be only through secondary care.

"So can GPs refer to your service, that's really…?" (CC3)

"Yes certainly, absolutely yeah". (OT2)

"That's interesting. Why don't we know about it?". (CC3)

The lack of a structured organisation of services meant that a large number of referrals to neurorehabilitation teams came from a small group of practices who knew about the service.

Lack of organisation

There was confusion on the role of different stakeholders in the process of returning to work after a stroke. Participants were unaware of differences between the role of an Occupational health department and an Occupational Therapist. Moreover, stakeholders including the employer representative and the GPs were not aware of what sort of role an OT could have, such as issuing Health and Work Reports that patients could use to claim employer's sick pay for short-term absences and to support GPs filling sick notes,[17] liaising with family members, Occupational Health and work managers and giving recommendations about work. In addition, only the few patients had experience of the OT services ongoing at the time of the study.

I think you're right. Yeah, ensure a patient has occupational health review and I must say I don't know what else to do from an employer's side and I don't fully understand actually where occupational health and you guys [OT] come in in a way… does that mean I should be referring them so they are having occupational health, but can you see them as well, or is that a waste of NHS resources. (GP2)

As neurorehabilitation services are not centrally organised and need referral from primary or secondary care, it is not available to all patients, especially patients suffering from invisible impairments such as fatigue, memory and concentration problems.

"…however there are sometimes people being missed as well, I don't know why that happens though, I had a patient a while ago […], was properly mobile and I think that's when they

decided he didn't need community services at home, but it turned out that he was really struggling and got through the GP and physio direct back to us, so it still happens that people get lost in the system somehow" (OT2)

The importance of OT support

Patients who suffered from the stroke more recently and had access to the local OT service (the neurorehabilitation team) highlighted their important role in facilitating successful return to work.

I keep singing their praises, the neuro health rehab team and Remploy, she [OT from the neurorehab team] *brought Remploy in and somebody else, I can't remember who they were, basically a contractor saying "Right, this is the chair he needs, this is the software he needs, this is the computer keyboard he needs, make sure he's got a parking space within a reasonable bit of the building"…if I'd actually gone back to work, that would have been the absolute very solid concrete help. (P3)*

Stroke survivors described that an important role of the neurorehab service was to connect people who suffered from a stroke and enable peer support.

"I got discharged from hospital and then really you're not dealing with anybody else in your predicament…and it wasn't until again the neuro rehab team last summer set up a returning to work, there was like eight sessions over eight weeks … well I met other people in the same boat and that was quite an eye-opener and also it's very, very encouraging." (P3)

Linking with other services

A lack of communication between GP surgeries and other services as well as agencies such as job centres and occupational health departments was pointed out. OT and clinical commissioners mentioned the importance of linking with other services, getting to know what is on offer and how they could be linked together for stroke survivors of working age, though the ongoing changes in the service structure was making the process challenging.

"...we're beginning to have conversations with the whole mental health team really because we've now joined together so I think in six months' time I'd hope to be able to sit round a table and say we've actually made some movements there to link the two services together. Because obviously they've got Recovery College, they've got all sorts of things there and we're now in the

same organisation but as professionals we're not yet getting together and we need to begin to make those contacts." (OT2)

A major problem for neurorehab team being able to offer their care to the local stroke population was their limited capacity, and that the service is paid a fixed amount/year, rather than being commissioned based on demand.

"The other problem of course is how much capacity you've got because if all GPs suddenly think "ah I've got three patients .. for you"…you consider the number of practices just in City itself that you deal with, you could be swamped. (CC3)

Commissioning such neurorehab service, though, was considered challenging without a strong financial argument for cost-benefits.

[…]. Yeah, and then have to be a financial argument for doing that as well, I mean that's the biggest thing." (CC2)

Another barrier to linking the services together could be the commissioning model. In the case of mental health, commissioning is separated from non-mental health, making the linking services challenging.

"...low motivation, depressive symptoms go up and that then makes it, you know, that is non-synergistic with doing anything else like getting back into work and, you know, mental health services are quite separately commissioned etcetera, than physical health. …we can't necessarily suddenly transfer loads of funding to one organisation to do it because the other organisations will complain but you could find a way of integrating these psychological support programmes better with stroke." (CC1)

<u>Improving communication: A rehabilitation assessment integrated with the electronic record</u>

Through the topic guide, participants were prompted to discuss a potential online rehabilitation assessment tool to provide a post-stroke picture over time of patient needs and functional impairments, which stroke survivors and their carers could access and share with interested parties.

Stroke survivors and carers liked the idea of an objective assessment tool they could fill in and help them to become aware of impairments and problems, considering some patients may lack insight.

"...a tool to actually try and figure out where you actually really are, and what actually the picture of where you might be, as opposed to as I say my own very subjective position."(P3)

Other stakeholders were also positive about the possibilities of an online tool. GPs were particularly interested in quick access to a patients' up to date functioning.

"...I think that's perfectly reasonable actually, so especially if it were, I think in a template form so I can actually just tick on a certain area and then I get a kind of functional status of the patient which is the most recent,...I think that is a bit like the End of Life care, it's something that should be very easily, ...that would reduce our time". (GP2)

The sharing aspect of such a tool was also recognised as important by stakeholders.

"...a lot of places are looking to read-only access to other people's systems...SystmOne can get overloaded if everyone is writing into it, but offer practices that want to, anyone who wants a widget where they can see what the psychologist is doing." (CC1)

Another major concern is the privacy of patients and appropriate access to shared personal data.

"... I would be very careful about whole else has access to all this data…you might not necessarily want people to have access to some of that." (P8)

A potential solution that was mentioned by patients is the idea of a compartmentalised online record, so each party could access only information relevant to them.

<u>Improving communication: a patient-held shared-care plan</u>

Stroke survivors discussed the problem of remembering the plan communicated to them by healthcare professionals and that a written report might greatly help.

"Yeah. I think the written record is a very important, I mean I sometimes when I go to see a specialist nurse or something like that and my daughter asks me when I get home "what did he say?" and I've lost half of it" (P1)

Other stakeholders mentioned the missed opportunities in discharge documents/a shared care plan. For example, GP and Clinical Commissioners commented that meaningful cognitive screens, management plans and information about community services are not always included in hospital discharge letters.

"...that's a real lost opportunity not just to send a simple letter at the point of discharge to the patient, the GP saying "here are the long-term services available and here's how you get back into them if you're having problems". Why are we not doing that? (CC1)

"Yeah. It's about empowering the patients actually and signposting them, kind of making them aware of what's there." (CC2)

Discussion

Summary

This study explores the role of primary care in supporting stroke survivors in returning to work including perspectives of a range of stakeholders. There were a mismatch between patient and carer needs and what was provided by primary care and a lack of coordination between primary care and other services.

Strengths and limitations

The strength of this study lies in the participation of a range of different stakeholders from a local community. The key limitation is that the small sample of participants was from a single geographical area.

Comparison with existing literature

Patients and carers discussed a range of issues with stroke-related impairments and their assessment, especially in relation to invisible impairments, consistent to what has previously been reported by participants of an online forum.[9,18] In agreement with a previous study,[19] we found that access to services relied on brokered provision and tacit knowledge. The timing of vocational rehabilitation interventions was complex and there was a substantial degree of unmet needs. Investment in non-acute stroke services was seen as "non-essential" due to competing commissioning priorities. Primary care providers lacked training and cross-sector partnerships were weak.[19] Results are consistent with and partly explain the variability in the rate of return to work post-stroke reported previously.[2] Effective use of the GP fit note scheme is hampered by difficulties with assessing stroke-related impairments and their effect on return to work, in particular in respect to fatigue and cognitive issues. Rather than GPs opting for the easiest option of signing stroke survivors off work, [13] we found evidence of employers asking clinicians for sick notes rather than undertaking work adaptations, suggesting they face similar difficulties with assessment of post-stroke impairments and work adaptations.

Implications for research and practice

The results of this study have several practice implications for improving success rate of re-employment after stroke, while taking into account the current pressure on GP workforce and budget constraints of clinical commissioners.

Although findings showed that primary care currently has a limited role, there is need to increase awareness of the potential key role of primary care in vocational rehabilitation after stroke. This includes addressing unmet needs in case patients have fallen through the net, coordinating care and communication among the different services involved. As fatigue and cognitive impacts on return to employment extend well beyond two years post-stroke, services need to be responsive to the changing needs of the stroke survivor throughout their recovery process and have better mechanisms to ensure re-entry into stroke vocational rehabilitation.[19] Three solutions have been put forward to help patients returning to work after stroke. These proposals are integrated within GP consultations and primary care to minimise workload, while addressing unmet needs: a rehabilitation assessment that is part of the electronic health record to figure out 'where they actually are' in terms of rehabilitation and functioning abilities related to their work; a designated nurse within the GP practice dedicated to issues of post-stroke employment, with knowledge of local services including community and specialist neurorehabilitation services; the enhancement of the opportune sharing of the electronic medical record with parties involved in the return to work process.

Patients and their families face rigid rules about sick pay and often have to make a decision whether going back to work at 28 weeks (6 months) and by 1 year poststroke, when their recovery might still be ongoing. The Equality Act 2010 oblige employers to consider whether 'reasonable adjustments' could help stroke survivors return to work, provided there is an assessment of their impairments/disabilities. This is more straightforward for physical impairments and primary care might be the only source of help for patients whose invisible impairments have not been highlighted and are exacerbated by return to employment and for stroke survivors who are self-employed or business owners. Primary care is in a crucial position to support stroke survivors successfully returning to work and address inequalities in access to vocational rehabilitation support. This aligns with the United Kingdom Acquired Brain Injury Forum campaign to raise awareness of the rehabilitation prescription.[20] Research is needed to develop the three suggestions emerged from this study into interventions, addressing potential problems together with their evaluation in terms of cost-benefit. Commissioning investments into non-acute stroke services such as stroke vocational rehabilitation is challenging without the evidence to support their cost-effectiveness.

There is need of gathering evidence around the cost associated with the current suboptimal lack of rehabilitation support in the community and balance it against reduced health and social care resource use and the wider health benefits of maintaining employment.

P	G	Y		Time since stroke (years)	Impairments		Employment before stroke		Employment after stroke	
					Physical visible	Non-Physical Invisible	Working time	Job type*	Working time	Job type*
P1	M	Not disclosed	TIA	30	-	+	Full time	4. Small employers and own account workers	Full time	4. Small employers and own account workers
P2	M	55	Stroke	2	+	+	Full time	4. Small employers and own account workers	Part time	Volunteer work
P3	M	51	Stroke	1	-	+	Full time	3. National Government Administrative Occupations	No	-
P4	M	Not disclosed	TIA	7	-	+	Full time	2. Laboratory technicians	Full time	2. Laboratory technicians
P5	F	65	TIA + stroke	8	+	+	Full time	3. National Government Administrative Occupations	Part time	3. National Government Administrative Occupations
P6	M	50	TIA + stroke	0	+	+	Full time	5. Plumbers and heating and ventilating engineers	No	-
P7	M	58	TIA	2	-	+	Full time	1.2 Chemical scientists	Full time	1.2 Chemical scientists
P8	M	60	Stroke	4	-	+	Full time	2. Managers and proprietors in other services NEC	No	Volunteer work
			Carers Relationship with stroke survivor							
C1	F		Wife of N.1							
C2	F		Wife of N.6							
	G		**Profession**	**Work details**						
OT1	F		Occupational therapist	Specialised neurorehabilitation centre						
OT2	F		Occupational therapist	Local Community Neurorehabilitation Service						
GP1	M		GP	Practice of 11,000 patients						
GP2	M		GP	Practice of 8,000 patients						
E	M		Employer Representative	>500 staff						
CC1	M		Clinical Commissioner	Mental health						
CC2	M		Clinical Commissioner	Occupational health - stroke services						
CC3	M		Clinical Commissioner	Heart and stroke medicine						

Table 1

Study participants. P: participant reference. G: gender. Y: years.

* Job type classification according to the SOC2010 and NS-SEC Occupation coding tool.[21]

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Ethical approval

This study has received ethical approval from Cambridge Central Research Ethics Committee (REC reference: 15/EE/0133), IRAS project ID: 171328.

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Competing interests

None declared.

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