Abstract

Purpose. Guillain-Barre´ syndrome (GBS) is a transient inflammatory disorder affecting peripheral nerves, characterised by weakness and numbness in limbs, upper body and face. Residual problems affect a large minority, and complicate return to work. This qualitative study explored the experiences of people who returned to work following their diagnosis of GBS and recovery, to gain insight into factors that facilitated or inhibited this process.

Method. Five people participated in in-depth interviews. Individual and common experiences were explored through interpretative phenomenological analysis.

Findings. Three recurring themes are presented: the perceived value of work; losing and recovering a familiar identity at work; and dilemmas around using support and adaptations at work. Certain individual issues also emerged but are beyond the scope of this article. Participants tended to measure their recovery in terms of returning to work yet continued to experience certain physical and psychosocial difficulties at work related to GBS, which required active coping strategies. Limited public awareness of GBS was perceived as a hindrance when returning to work.

Conclusion. This study provides a rich account of the experiences that people encounter returning to work following GBS. Rehabilitation specialists may offer more effective preparation for this process, drawing upon the issues identified.

Introduction

This study elicited the experiences of people returning to work following an acute or sub-acute onset of Guillain-Barre´ syndrome (GBS), with the aim of uncovering the meanings of employment in their lives, and their experiences of managing their return to work. The subject of work and vocational rehabilitation is of real interest within rehabilitation both in the UK and internationally, encouraged by government policies which aim to increase the number of people with health problems and disabilities returning to work [1]. Rehabilitation specialists therefore need to appreciate the potential problems that people may experience in returning to the workplace following neurological damage and their suggestions regarding appropriate support. GBS is the most common cause of acute flaccid paralysis. Its annual incidence is 1–2 per 100 000 population, with almost twice as many males as females being affected and incidence rising with advancing age [2]. Patients with this disorder present with rapidly progressive tingling, numbness, weakness, pain and disturbances of autonomic functions. Weakness can be distal, proximal or both. Tendon reflexes are lost early. Patients can have facial and bulbar weakness and sometimes ophthalmoplegia. Speech and swallowing problems are common [3]. The progressive phase usually lasts 2–4 weeks. In one study, more than half required ventilation [4]. These patients had a significant risk of

mortality, survivors were left with the greatest long-term sequelae. For most, gradual recovery begins after a few days or weeks and continues over several months, though progress is very variable. Bersano et al. [5] reported that 21 out of a total of 70 participants identified that they were not able to perform their usual activities, such as outdoor walking, sport or housework 2 years post-onset. Similar findings were reported by Bernsen et al. [6,7].

A detailed search using the terms 'Guillain-Barre´ syndrome', 'work', 'vocational rehabilitation', 'quality of life', 'follow-up', 'activities of daily living' and 'occupation' of the databases Medline, PsycInfo, AMED, CINAHL, British Nursing Index, Pubmed and Cochrane, revealed that previous research into the long-term effects of GBS on work was sparse and mostly used quantitative methods. Bernsen et al. [6]reported that 62% of patients were able to return to their previous employment post-GBS, however the remainder needed alterations at work, to reduce its physical demands or their responsibilities. Less than half of patients returned to work within 2 years in the study by Forsberg et al. [8], and some of these could only manage reduced hours. A need for part-time work for an extended period after GBS, or early retirement, has been noted in other studies [6,7,9,10]. Many researchers suggest that residual physical impairments following onset of GBS are responsible
for changes to work patterns, specifically loss of power [6,7,11,12], muscle pain [11], disturbed sensation [6,12] and fatigability [5]. But physical impairment may not be the sole explanation [9]. Bernsen et al. [13] found no significant correlation between the final physical condition of people post-GBS and the psychosocial dimension, assessed using the Functional Assessment Scale and the Sickness Impact Profile. Furthermore, Bernsen et al. [7] highlighted that psychosocial impairment was seen in large numbers of patients with GBS included within their studies, even those left with no or mild physical impairment. One criticism of the quantitative research concerns the limited sensitivity of many of the tools used to assess long-term problems in terms of impairment, disability, roles and occupations. For example, the Modified Rankin Scale has been criticised [4,5,9]. Even though this scale provides a good measure of physical impairment, it may be inadequate for evaluating how residual impairments may hamper people's lives in relation to their occupational and social activities. Ceiling effects have been noted in the Barthel Index [4,8]. For example, Nicholas et al. [4] noted that some people with GBS recorded relatively high modified Barthel Index scores of 20,yet were still be unable to perform activities such as returning to work. Clearly, there are complex factors underpinning return to roles and occupations in addition to measured physical disability.

The evidence to date identifies that physical and psychological problems continue to affect a sizeable minority of patients, for several years post-onset of GBS. These problems are reported to have a considerable impact upon performance of everyday activities, including work and health-related quality of life. However, rehabilitation specialists have limited evidence about how these factors subjectively influence the process of returning to work, and how people manage this process successfully. It has been suggested that when researching a subject, which has very limited pre-existing knowledge, or is complex, dilemmatic or novel, a qualitative approach may be particularly useful [14].

Aims of this study

This study used a qualitative method to explore the following research question:
'What are the experiences of adults returning to work following recovery from GBS?'

The specific aims were to investigate in greater detail participants' motivations for returning to work after GBS, the subjective impact of GBS on their ability to return to work, and how they managed their return to work.

Method

Methodology

This study employed Interpretative Phenomenological Analysis (IPA), used increasingly frequently to analyse and interpret interview data concerning experiences of health and illness [15,16]. This approach seeks to understand individuals' personal perceptions or accounts whilst acknowledging that access to the participant's personal world is the result of interactions between the researcher and participant and that the process involves interpretative activity on the part of the researcher. Furthermore, IPA acknowledges that the process of gathering and interpreting data is both dependent upon and complicated by the researcher's own beliefs and experience, which cannot be simply set aside or 'bracketed'. The data are not collected with the intention of generalising to a larger population, but to enrich understanding of the lived experience, as is typical of phenomenological research more generally [17].

Ethical considerations

Approval for the study was sought and given from the host university and then by the relevant National Health Service Trust. Clear information sheets were given to participants, who were invited to ask questions before giving written consent. Careful considerations were given to preserving the confidentiality and security of the data. Participants were assured they could stop taking part at any time without putting at risk any treatment they were having at the time of the study, or might have in the future.

Recruitment and participants

Participants were selected from a database of patients, who had been admitted to a specialist rehabilitation unit between 2000 and 2006. Those invited to join the study met the following criteria: diagnosis of GBS, had returned or attempted to return to work following their illness (identified through the long-term goal specified within patient's discharge reports, and confirmed when consenting to participate); lived within a 60-min journey of the specialist unit. They also had to have a good understanding of the English language and the ability to give written consent. Sixteen patients met the criteria and were sent information inviting them to participate within the study. A total of five patients (four men, one woman) volunteered, all of whom were currently back at work. This is an acceptable size of sample for an IPA study as long as rich data are gathered from each participant [18]. As is quite typical of qualitative research, it was not known why some of those contacted did not take up the offer of participating, and it was thought unethical to ask for reasons. Table I gives individual details of participants. This shows that one participant (David) had not received intensive care and so

had presumably been less affected by the condition than the other participants. However, his return to work was still delayed and complex, partly because his residual symptoms raised safety issues for his work as a train driver. As all participants were treated in a leading London hospital, it can be assumed that they received medical treatment that followed best evidence at that time. However, further details about any variation in their medical treatment whilst inpatients were not available to the researchers. To ensure the anonymity of participants, pseudonyms
have been used.

Interview

Participants were interviewed between 1 and 5 years after their admission to hospital with GBS. They were offered a choice of location. Four participants chose to be interviewed within the specialist unit and one participant was interviewed at home. Semi-structured interviews, lasting 60–90 min, followed the participants' interests or concerns rather than a fixed agenda, because the phenomenological approach acknowledges the participant as the expert on the subject being investigated and views the role of the researcher as facilitating the conversation. The interviews started with a general invitation, 'Tell me about your experiences returning to work after GBS'. This was sufficient to generate the beginning of a free-flowing account of each participants' experience, with additional questions asked as needed to address the aims of the study.

Data analysis

Analysis of the data followed the recognised process of IPA [15,16]. An idiographic, case-study approach was employed, based on close, repeated reading of each transcript. The analysis involved a lengthy, iterative process by each author, followed by discussion, thereby increasing its trustworthiness. This included looking for themes in the first case, looking for connections between emerging themes, compiling a master list of themes, continuing the analysis with other cases, compiling a list of recurring themes for the group and then searching for a small set of superordinate themes that summarised the participants'
experiences, convincingly. Attention was also given to the unique features of each account, and the ways that the individuals' accounts differed even when reflecting on certain commonalities in their experiences. There is insufficient space to explore the more idiosyncratic issues that emerged. Careful re-review of transcripts enabled the researchers to determine whether the salient issues had been captured satisfactorily by the themes and commentary. The analysis benefitted from the different professional backgrounds of the researchers (an occupational therapist and a health psychologist) as each was sensitised initially to certain different issues. For example, descriptions of routines and supportive adaptations were more salient to the occupational therapist, and dilemmas about accepting disability were initially more salient to the psychologist. Yet, through discussion and further analysis, both perceived such issues as subjectively important within the participants' accounts. A more nuanced analysis was achieved than seems likely had both shared the same professional background.

Findings

A large number of themes emerged during the idiographic stages of data analysis that concerned individual participants and complicated their experience of return to work. For example, one participant attributed the onset of GBS to severe stress, so became diligent about limiting his responsibilities at work. *'. . . I try to work completely stress free now I try to get every bit of stress out of my working life'* (David). Another had suffered heightened anxiety from witnessing the deaths and distress of patients during his stay in intensive care during the acute phase of GBS. *'It is such a nasty illness to start with because you are in Intensive Care for quite a long time and whilst I was in Intensive Care I saw two people die . . . of course I couldn't even turn away because I couldn't move and it was pretty awful from that point of view'* (Edward). He acknowledged that his intrusive thoughts and anxiety affected his attendance in the early weeks of returning to work.' *. . . So some days when I phoned in and said I'm not coming in today it wasn't necessarily because my legs weren't working properly or I didn't feel strong enough physically, it was mentally I didn't feel strong'.*

Such traumatic experiences of intensive care and feelings of extreme vulnerability have been noted in previous qualitative research [19], but their impact on returning to work have not been highlighted. A further exploration of each idiographic analysis is beyond the scope of this article. Instead, we focus on three recurring superordinate themes emerging across the interviews. These concern the perceived value of work; work as both challenging and re-establishing a familiar self/identity; and dilemmas around support and adaptations at work. Work, for these participants, was a marker of return to a 'normal life' and 'normal self'. Their experiences resonate with the observation made by Charmaz [20] that valued occupations are used by chronically ill people as markers of their self/identity and as measures of the extent to which the self has been preserved or disrupted by illness. Some distinct issues that emerged in the context of GBS will be examined in the discussion.

Perceived value of work

Returning to work was viewed very positively by all participants. Primarily, it was perceived to be a significant step to moving on with life and putting GBS firmly into the past, *'a desire to move on and get this thing behind me. One of the best ways of doing that is going back to work, definitely'*, (Andrew).

The opportunity to be employed and actively participate once again at work enabled participants to achieve a sense of normality, and distance from GBS.
'I want it all to be forgotten, as if it never happened . . . so I'd rather be back, I'm quite happy to get back into normal life', (Andrew).

David also associated returning to work with normality. He described how his frustration increased when his physical recovery slowed down, and his anticipation that work would offer a new catalyst for change. Juxtaposing *'going back'* and making a *'step forward'*, suggested that return to work was a pivotal moment in the GBS trajectory.

'I had been sort of moping around . . . trying to pass the time to get better, about 3 months by then, and I got to a stage where nothing was happening, it probably was but I thought nothing was happening and my life, it wasn't my life . . . I felt that nothing was making anything change so I thought maybe it was something in my head, so if I go back to work, go back to a normal life at least it will be a step forward'.

Relating to colleagues made an important contribution to feeling 'normal' again.
'I think probably a lot of people thought I was coming back too early. That's not really for them to say, but I think that they were surprised I came back so soon, but I think it is important to get back on board, need the company and intellectual stimulation. Brain was starting to numb out a bit, definitely, and you know it's quite a close knit company that I work at. I consider them all to be friends as well, so there is a support structure there and also just a desire to move on andget this thing behind me. One of the best ways of doing that is going back to work, definitely', (Andrew).

The value placed on regaining the camaraderie and stimulation offered by colleagues was mirrored in the narratives of both Edward and Beth, who described their colleagues to be '*more like friends'* and '*like a family'*. Returning to work offered the opportunity to re-develop these close relationships.

The financial benefit of working inevitably motivated return to work. Financially, Colin found being out of work (for the longest period of all the participants) a huge struggle and reported dissatisfaction with the lack of financial support received from disability benefits:
'Somebody had told me to apply for benefit whose name escapes me which I didn't get but I think I ended up with about thirty pounds a week benefit and then I realised I had to try and get back to work as soon as possible'.

But remuneration was never the sole motivation. David, who lived alone, valued the sense of purpose and structure that working gave to his life, more highly than the financial benefit.
'I need something to structure my life, to organise my life, it's not all about money, money is important obviously, but it is not all about money, it's about having a purpose in life'.

Participants valued work for providing a purpose and a focus to life.
'I think the routine's good' (Andrew).
'That's what you get up in the morning for' (David).

In addition, participants desired increased levels of physical activity;
'fed up with being inactive . . . wanted to get out and do something' (Colin).

Furthermore, there was a suggestion that working had a positive impact upon behaviour and provided clear direction;
'It keeps me in line, it keeps me in order, it gives me a goal' (David).

Work also helped to place GBS in a more peripheral, controllable place in participants' lives. It offered a distraction from the residual problems left by this illness.
'*So if work takes up a third of my day that is a third of my day not to worry about.*' (David).

Some thought work helped them to recover physically. Colin, for example, used his journey into work as an opportunity to increase his levels of physical exercise, an activity made difficult by numbness in his feet;
'*. . .the job, it was probably therapeutic for me because I didn't use to go to the depot in my car . . . it gave me a mile walk, about three quarters of an hour walk down to the depot which I thought was therapeutic . . . it was therapy for me but I was getting paid for [it]*'.

Work both challenges and restores a familiar self
Participants demonstrated concerns about their altered appearance and functioning, and experienced work both as highlighting their changed selves and also as instrumental in restoring self-confidence. Their accounts revealed that they were sensitive to the reactions of others at work, and that their 'normal', recovered selves became fragile when colleagues' behaviour changed towards them. Beth, for example, seemed concerned about others' reactions to the speech impediment that had resulted from GBS:
'*To start with I was really self-conscious and I still I am a little, but not as much as I was. Colleagues actually seeing my lips don't move in the normal way and I know that sometimes I would say a word and I was quite sure that they knew what the word was but they got confused . . . they wonder what's going on, but no-one actually normally says anything*'.

Colin, likewise, expressed embarrassment about his altered appearance:
'*I say to my wife, ''Do I look as though there is something wrong with me?'' It's only a slight bit of numbness but it feels as though I'm not speaking . . . it feels as if the mouth's not moving as it was before, and you feel a little bit self-conscious really because you're not the same as you were*'.

David had a similar concern when he first went back to work:
'*People look at you and think what's the matter with him? No honestly, work is okay now, [but] when I first went back I did have to concentrate very, very hard because I didn't want to draw attention to myself*'.

Most of the participants dealt with potential loss of self by trying to conceal their impairments, or by avoiding discussion about them. Beth was a journalist, who had just begun to carry out face-to-face interviews once again at the time of participating in the research project. Although she was aware of her speech problems, she chose not to refer to these or disclose her diagnosis to her interviewees;
'*[With] a few people, I have noticed that sort of slightly questioning look in their eyes as if they might hear me not be able to pronounce a few words or something. I don't know if I am just being paranoid there . . . they look like they are thinking ''I wonder what happened?'' or something like that. I don't know if they are, generally no one has said anything [whom] I have interviewed*'.

Despite its capacity to challenge, participants also emphasised that work had a particular role to play in helping them to re-establish their pre-illness selves.

'That [work] was good for me because I was normal again, I thought I was the same as I was before I had the Guillain- Barre', I was the same person again. Obviously I wasn't but I thought I was, and that was good enough for me' (David).

For four of the participants, an acceptably 'normal' identity required rejection of overt disability. They presupposed that other people had negative social attitudes towards disabled people, and had apparently internalised such attitudes themselves. Given the central problems of stigma, it was understandable that Colin did not inform his employment agency about the residual effects of GBS when signing up for a job as a driver for the local borough council:

'. . . I must admit I didn't tell them I couldn't feel my feet.'

Nor did he want to disclose his diagnosis to other drivers in the depot:

'Nobody knew what had been wrong with me'.

Colin expressed concern that disclosure might put his job at risk, *'. . . they may make me pack my case . . .'* His symptoms also presented safety concerns in the workplace, which he managed by delaying return to work and by concealment. In contrast, Andrew was unique in this sample in being relatively open about his diagnosis and residual difficulties with colleagues. He did, however, monitor colleagues' behaviour for possible negative responses, and sought to exert some control over these:

'I felt like going back the first day, why don't I shave my head or wear orange? That will really freak them out and then I'll have a laugh, but [they'll] then realise he's back to his own tricks'.

Unlike the other participants who disclosed as little information as possible about their health to work colleagues, Andrew actively confronted his colleagues both about his needs at work and about his illness:

'Because people won't engage me as they would have done previously in the work place, so sometimes I have had to sit people down and said ''Look, I'm looking you straight in the eye, I don't want you to accommodate me in any way, but I just want to discuss this particular issue, because it might cause grief for you or me'''.

His senior position in the company, and positive relationships with colleagues, may both have been contributory factors that helped him to withstand the scrutiny of others without feeling demeaned.

David seemed to cope with threats to his self-image by entering a 'supernormal' phase on his return to work, doing as much work as possible, and refusing extra help:

'I just couldn't get into work quick enough every day. I would do any job they wanted even the ones that other people didn't want to do . . .'.

Dilemmas around accepting support and adaptations at work

Possibly, because participants sought to recover their 'normal' pre-illness selves through returning to work, they were ambivalent about accepting support from colleagues and managers, and also making other adaptations (for example, modifying tasks or working hours). When David was asked during the interview if he would have liked some additional support returning back to work, he expressed strong resistance;

'I didn't want anybody to help me to go back to work to be honest. I was happy I wanted to do it on my own because I didn't want anybody to, if you like, know the truth about what I was, how I was feeling at the time. I really wished, I don't mean to be ungrateful, I wished they would just leave me alone and let me get back to my job and do my job again, but you can't say that because they have been so nice about it'.

David perceived that rather than strengthening his position, additional support at work made him feel much more vulnerable, perhaps threatening the 'healthy', capable image that he was seeking to portray to others, and possibly even threatening his job security.

During the initial phase of returning to work, participants fluctuated between appreciating colleagues' support and finding them over-protective:

'It was strange . . . the first ten days I would say were strange because people treated you with kid gloves as if there was something wrong with you . . .' (David).

Beth also commented that her colleagues were overly supportive *'. . . so they are really understanding and kind and stuff and offering to do stuff . . . which I didn't really need them to do for me'.*

Despite perceiving initial support from colleagues as potentially demeaning, some participants did encounter difficulties in performing their jobs when it was withdrawn. For example, Edward described how the support initially given by colleagues soon dwindled:

'The first couple of weeks, everybody is saying oh and how are you feeling and saying have a seat, don't get up and being really, really lovely . . . but once that passes, it passes very quickly, and all of a sudden you are just expected to do everything and you try to do everything and it's not possible'.

Adaptations at work were viewed by some, but not all, as positive. Access to such supports and modifications to the job seemed to be facilitated by participants' position in the workplace hierarchy and their degree of autonomy. For example, two were senior managers within their respective companies,

'I am sort of senior partner of the firm' (Andrew)

'I am in a lucky position in that I am a Director of a company' (Edward).

This afforded them a great deal of flexibility regarding their routine and role on returning to work. For example, there was no need for Edward to formalise a return to work plan, or even be open about his residual difficulties, due to his senior position within the company, *'I didn't have sort of like a big office where I would have to see someone to come back to come to*

work . . .' and this high level of control offered him considerable flexibility both about his duties at work and his working hours. He described being able to return home without explanation or reference to GBS if he felt unwell '. . . *because I am a Director I can just say I'm going home . . .'* and the freedom to stay away from work if necessary, *'[In the early stages] I'd feel I can't face work today and I was lucky enough to ring in and say I'm not coming in today'.* Although Edward was the director of his company, on his initial return to work he chose to perform an administration role, which would allow him to work at his own pace and with very little pressure;

'. . . so when I first went back . . . I was dealing with a lot of back office things, so I was dealing with a lot of post, really boring, I was more like the office junior . . . they were things I could do at my own pace . . .'.

It is possible that seniority also helped to challenge the potential stigma of illness. Andrew, of all the participants, appeared the most aware, open and accepting of the functional impairments that persisted after his illness. He described altering his work-role permanently to focus more closely upon his strengths. But his successful adaptations were not purely dependent upon his personal attitudes and coping strategies. Through his management position he had the authority to employ a personal assistant to carry out other areas of his job, '*so what I was able to do was actually go out and employ someone who was much more specific to the needs that I now have'.* It was also the nature of his job that allowed him to work at home, through use of computer technology '*I have got a facility to work from home as well'.* Andrew was particularly open about his residual difficulties and needs post-GBS:

'Well, I still have a trouble with tiredness . . . on the mental side I think it's definitely harder to concentrate and definitely get distracted easily . . .'

This level of acceptance may have facilitated his decision to reduce the number of days that he went to the office from five to three (Tuesday, Wednesday and Thursday). He decided to use Monday and Friday as 'buffer days', in order either to prepare for work, or gain sufficient energy for leisure activities with the family at the weekend;

'Friday is like a buffer day . . . I think that's quite important and basically you know, I can have a good sleep, have a breather and recharge my batteries and then the weekend is for the family and Monday is a buffer day similarly at the other end . . .'.

Other participants also made changes to their roles, to ease their transition back into work. Yet these were regarded as temporary, short-term changes that would soon lead to a full return to previous responsibilities. Beth, for example, was a junior member within her team, yet she enjoyed a degree of autonomy regarding her work role, thus facilitating a graded return to work. For example, she was able to carry out telephone interviews only initially, with a plan to gradually increase the number of face-to-face interviews as she became more confident in her facial appearance and self-presentation;

'kind of a lot is left up to you normally deciding you want to go and interview someone face-to-face'.

Although most workplaces offered some flexibility at first, this was usually only possible on a short-term basis. For example, on their return, David, Andrew and Edward all reported colleagues' demands that they return their usual tasks. But only Andrew and Edward had sufficiently senior positions to resist taking all aspects of their job back, '. . . *You've got to be careful not to take all that . . . back on . . .*' (Andrew), '. . . *I've said no*' (Edward).

Early return to full responsibilities was not, however, simply associated with limited power or lower status at work. The personal values of individuals seemed important too. David, for example, totally rejected a graded approach to returning to work as a train driver, even though offered the opportunity to perform light duties, such as working in an office or delivering mail on trains. However, for David, this was not an agreeable outcome, 'It would only have been a half-way achievement to me . . .'. David placed significant importance upon returning to his previous role and working at full capacity from the onset, '*I wanted to achieve all or nothing . . . I will come back if I can come back with the intention of driving a train, not working on a station or something like that*'. Although David was keen to carry out his role as before, he did make permanent changes to his hours of work to address his over-riding priority of managing stress more effectively (as he saw stress as contributory to his illness). David chose to do '*sensible hours*', instead of working shifts, as he believed that shift working, '*isn't good for your health*'.

Resources within the work place were also important for facilitating satisfactory return to work. For example, Andrew experienced both physical and mental fatigue associated with the GBS, which he managed satisfactorily through taking rests during the day. As noted above, this participant was unusual in his willingness to disclose his difficulties. But he was also fortunate in working in an environment which had resources for resting during the day.
'*I was able to drift off into the meeting room and have half an hour's kip on the sofa, which everyone was totally okay with . . . if you do that during the middle of your working day, it completely recharges your batteries*'.

Edward had a high status within the workplace which allowed him to manage his working life without giving others very much explanation. He was aware of the need to take regular rests and to pace himself during the day '. . . *it takes me longer in the morning to get going, then I have my shower and then I have a little sit down and I just do it at my own pace.*'

However, in contrast to Andrew's work environment, Edward's work environment did not provide a quiet rest room, and he did not feel able to request such an area, '*You can't do that [rest] at work, when you get to work if you've had a bad journey, you know, you can't have a lie down unfortunately*'.

Most participants perceived extra support as demeaning if continued for too long, and they prioritised re-establishing their 'normal' selves above comfort at work. Yet, there was some acknowledgement that health professionals could do more to educate the wider public about GBS. For example, although Edward was a joint director of the company he worked for and

had a significant amount of autonomy and control with regards to returning to work, he said he would value the provision of additional support from health care professionals:

'. . . I think you [health professionals] should speak to the Managers or the owners of the companies or Line Managers to actually talk it through because the only defence I really had was these proposals for returning to work . . .' [an A4 typed piece of paper completed by Edward as part of a goal that he worked towards, whilst an inpatient within the rehabilitation unit].

He explained that despite his senior position within the company, he still felt vulnerable returning to work:

'I had very little ammunition to be able to say I am not well enough without sounding like whingeing'.

Edward suggested that part of the problem is that GBS is rarely publicised and therefore most people do not have any insight into its long-term effects on physical functioning. Without knowledge or experience of the condition, managers and colleagues cannot be expected to know how to facilitate the return to work of their employees;

'A silly example, if somebody is pregnant, when they come back you know basically what to expect . . . and how to treat that person. . .but you can't blame the management, you can't blame work colleagues because [people] don't know . . .'

Discussion

The findings of this study support current evidence concerning residual physical difficulties, quality of life post-GBS, and people's sense of vulnerability [5–12,19]. All participants placed extremely high value upon work and regarded the process of returning to work as a very significant step towards moving forwards with their lives, and recovering health, cognitive stimulation, social relationships and a 'normal' self-image. These findings resonate with the qualitative accounts given by people who have successfully returned to work following spinal cord injury, or stroke [17,21,22]. Ville and Ravaud [23] found that people with paraplegia valued work for providing opportunities for social integration above financial benefits. Similar benefits have been noted among people living with other illnesses such as cancer and multiple sclerosis [24–27].

Although work offered opportunities for returning to a 'normal' or pre-illness self, it also increased concerns with difference and stigma. Fitting previous conceptualisations of stigma [28], participants typically responded to perceived stigma through concealing or avoiding discussion about their impairments. Participants were ambivalent about receiving support from colleagues and managers, and making use of adaptations at work. They recognised their practical helpfulness yet also feared associated stigma. To receive solicitations after their health challenged participants' identities as 'normal' and capable workers. Not all studies have found prevalent concerns about stigma among those returning to work with a chronic condition. For example, Medin et al. [17] found that people returning to work after a stroke welcomed the help and support of colleagues and managers, and were satisfied with a graded

approach when returning to work. Yorkston et al. [27] reported that people with multiple sclerosis seemed realistic about their physical impairments, developed proactive strategies to manage tasks at work, and welcomed appropriate support. These different attitudes to support and adapted ways of working may be accounted for by the *relative* invisibility of the residual impairments after GBS in this sample. This perhaps made concealment of impairments and presentation of a 'well' self more feasible, and participants may therefore have had less need to confront any long-standing personal prejudices about disability. Struggles over whether to disclose or conceal relatively invisible symptoms have been noted in other conditions [29].

GBS did seem to pose particular challenges in returning to work. Unlike spinal cord injury, and multiple sclerosis, for example, GBS holds a promise of full recovery. This possibility seemed to encourage a view among participants that their physical problems were temporary, further encouraging non-disclosure in the workplace. Charmaz [30] and Frank [31] observe that it is common for people to define serious illness in the initial stages as an interruption, thus perceiving it to be temporary, of short duration and with a predictable outcome (recovery). Such beliefs could easily be retained in the context of GBS, and may have discouraged participants from reappraising any negative assumptions that they held about disability.

GBS is also far less common than many other chronic conditions. Public awareness is, as a consequence, very low and participants mostly struggled to educate others at work, at a time when they felt their identities to be under threat. Factors such as high status, autonomy and environmental supports (e.g. rest areas at work; opportunities to work at home sometimes) assisted participants' return to their previous jobs. But greater public education about GBS might also be helpful. However, there was mixed opinion regarding the desirability of additional support from healthcare professionals with regards to returning to work. One view was that such assistance would authenticate the physical problems, but a second view was that providing such information to management and colleagues would only reinforce a disabled identity, thus resulting in a negative outcome.

Critical evaluation
The findings are inevitably dependent upon the quality of the interviews as well as the rigour of data analysis. Interviews are co-constructed by the participant and interviewer, and their contents are shaped by the experiences and expectations of both parties. In this case, the interviewer (the first author) was familiar with fatigue management programmes offered to patients with GBS and some questions seemed to reflect this knowledge. For example, with Edward, the interviewer asked the following leading question, rather than following the participant's agenda: 'Did you think very carefully about what you did at work so that in the evening and the following day you didn't feel the fatigue?' Yet participants mostly received open questions that invited rich narratives about their successes and struggles in returning to work.

Another limitation of this study is that all participants had previously received a specialist inpatient rehabilitation programme, which incorporated education and preparation regarding return to work. Perhaps because it addressed the issue of work, they had no criticisms of their rehabilitation (unlike the people returning to work after stroke in the study of Medin et al., [17]). But there was a risk that they might have communicated this taught knowledge rather than their personal experiences. Nevertheless, the variety of issues raised in the interviews and their contextualisation within their specific situations at work, suggested that participants were not in any simple way echoing professional recommendations.

The sample is small and cannot be said to represent people who have had GBS. Their original experience of GBS (and possibly their treatments) varied. Participants were all white British, middle class, and with English as their first language. There was only one woman. Three participants were office-based, one participant was a driver for a council within a London borough, and another participant was a train driver. Furthermore, a multiplicity of experiences affected each individual's re-entry into work. David, for example, had not spent time in intensive care and had not witnessed the potentially life-threatening nature of GBS. He lived alone and needed work to confirm a masculine self, and to provide a wholesome structure to his life. Hence, he might have been expected to make a smooth transition back to work. However, at 62 and nearing retirement, he felt vulnerable to being retired against his will. He struggled to return to work, related to his residual symptoms which created safety risks at work, his management's attitudes, and his own resistance to being 'demoted' in status. All individuals have distinctive stories to tell and the findings cannot in any simple sense be generalised.

Charmaz [32] suggested that chronic illness poses worse identity dilemmas for men than for women. She considered that masculine identities are largely gained through participation in work, sport, leisure and sexual activities and that chronic illness can alter or end men's participation in these activities. There were insufficient participants to enable comparison of males' and females' experiences of returning to work after GBS, and this might be addressed in further studies. Likewise, the interview did not explore the role of support (from partners or friends) for giving participants the confidence to re-enter work. This issue might also be examined further.

Positively, the credibility of the data analysis was enhanced through independent coding by the second author, and mutual discussion. The idiographic analysis also revealed distinctive issues in the lifeworlds of each participant that influenced return to work, supporting previous research that demonstrates both personal and environmental factors as jointly influencing this process [33].

Implications for rehabilitation
- Participants saw positive value and meaning in returning to work after GBS, supporting ongoing attention to vocational rehabilitation.
- Within the rehabilitation programme, consideration should be placed upon ways of educating and preparing patients in relation to issues such as identity change,

managing stigma, and possible dilemmas around receiving support and adaptations at work.

- Patients may benefit from having the opportunity to be supported in the workplace by staff with specialist skills related to neurology and vocational rehabilitation. This support may involve education of employers and colleagues where appropriate, yet the risks of increasing stigma and perceived difference also need sensitive consideration.

Further research

This study is the first of its kind, therefore the subject area would benefit from further qualitative studies involving larger sample sizes and both male and female participants from a wider range of social backgrounds and employment settings. Most urgently, this study focussed on participants who were successful in returning to work. Further studies would also be useful to explore in more detail the psychosocial and contextual factors that prevent people from returning to work after GBS.

Conclusion

This study has shown that return to work can be seen as a significant step towards recovering normal lives and identities after GBS. As well as financial support, work restored social relationships, provided impetus for activity, offered a focus and structure to life, and enabled people to reclaim their pre-illness selves. Nevertheless, participants faced certain dilemmas. In the workplace, there were occasions when perceived difference and stigma were accentuated, yet successful accomplishment of work tasks also restored a familiar pre-illness self-image. Participants reported dilemmas about whether or not to disclose their diagnosis, and many chose to preserve their previous identities by hiding residual impairments. Those who had more power and autonomy within the workplace appeared more able to manage their working patterns and to feel shielded from the negative judgements of others. A widespread lack of knowledge about GBS meant that colleagues tended to be uncertain about the person's needs. Self-advocacy was being required at a difficult time when people felt their self-image was under threat.

Support from healthcare professionals was perceived as having ambiguous consequences in the process of returning to work. Some participants suggested that professional support would authenticate their problems and provide useful direction to both themselves and their managers regarding the most effective way to manage the situation, whereas others felt it would reinforce their disabled status which they regarded in negative terms.

Successful return to work did not simply reflect physical recovery but was facilitated through individuals' positive attitudes as well as environmental factors (for example, having autonomy and control, thus enabling flexibility of hours and job responsibilities; having opportunities to work from home; access to a designated quiet room to take rests). It will be important to extend or replicate this work and incorporate the findings into rehabilitation strategies for people recovering from GBS.

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Table 1 Participants' details

	Andrew	Beth	Colin	David	Edward
Age of onset of GBS (yrs)	44	25	63	62	40
Occupation	Co-director and co-partner	Journalist	Local borough council	Train driver	Company director
Length of time in intensive care (days)	47	45	29	0	14
Length of time in rehab (days)	54	47	68	21	19
Barthel Index on discharge	20	20	20	20	20
Time from discharge to returning to work (days)	37	20	425	143	89