Return to work following acquired brain injury: the views of patients and employers

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**ABSTRACT**

Purpose: To investigate which factors are experienced as facilitators of or barriers to return to work (RTW), or as solutions to RTW-problems, by patients with acquired brain injury (ABI) and by employers.

Design: Qualitative study.

Method: Ten patients with ABI and seven employers participated in semi-structured interviews. Patients and employers were unrelated. Transcripts were open coded. Factors perceived to be facilitators, barriers, or solutions to RTW-problems were grouped on a thematic basis.

Results: Both patients and employers distinguished patient-related and work-related facilitators. When questioned about barriers, both patients and employers emphasized the importance of work-related factors such as sensory overload at the workplace and condition-related factors such as fatigue. Patients regarded poor guidance and support as barriers, while employers did not. Employers and patients suggested that solutions to RTW-problems were work-related, if necessary backed up by professional supervision. Patients also mentioned the need for understanding and acceptance of the limitations resulting from ABI.

Conclusions: Both patients and employers mentioned work-related and patient-related facilitators, work-related and condition-related barriers, and work-related solutions to RTW-problems. Patients mentioned lack of guidance and support as barriers, and stressed the need for understanding and acceptance of the limitations resulting from ABI in any RTW-solution.

> IMPLICATIONS FOR REHABILITATION

- Patients and employers are important stakeholders in the return to work (RTW) process of a patient with acquired brain injury (ABI)
- Professionals in rehabilitation practice, occupational and insurance physicians need to help patients and employers to realize RTW
- Professionals have to be aware of the perspectives of patients and employers regarding RTW, such as:
  - Little understanding of limitations resulting from ABI
  - Work-related aspects hindering RTW, such as sensory overload and high work pressure
  - Condition-related barriers to RTW such as (invisible) cognitive limitations and fatigue
  - Need for professional assistance during the RTW process

**Introduction**

Acquired brain injury (ABI) is an injury to the brain, either with a traumatic or a non-traumatic cause, that occurs after birth.[1] ABI often results in long-term cognitive, physical, behavioral, and emotional disabilities that can have an adverse effect on return to work (RTW).[2,3] It has been shown that only 40% of the patients with ABI, who were working before the injury RTW within two years after the injury.[4] This is an important finding, as about 75% of the patients with ABI are of working age.[3] Research has demonstrated that RTW is a crucial element in the quality of life of patients with ABI, providing a social environment, financial independence, and a sense of purpose.[5,6]

Given the importance of RTW, research in this field has focused on optimization of patient care to support RTW of patients with ABI. In this context a systematic review was conducted on factors associated with RTW after traumatic and non-traumatic ABI.[7] In summary, personal factors after traumatic ABI (education level, unemployment), and activity-related factors after non-traumatic ABI have proven to be associated with RTW.[7] Besides, another systematic review demonstrated that a combination of work-directed interventions, coaching/education, and/or skills training are effective for RTW after ABI.[8] These studies provide information to recognize patients for whom RTW is probably less likely [7] and which interventions might facilitate RTW for patients with ABI.[8]

However, it remains unclear how patients experience the RTW process themselves. It is recognized that patients play a central role in the RTW process.[9] Besides, it was shown that patients prefer to be actively involved.[10,11] The patient’s subjective experience...
provides crucial input for optimization of the RTW-process. As a key figure in this process, the patient himself can provide highly relevant insights on factors that he sees as facilitating or hindering RTW and what he considers to be effective solutions to problems in this context.[12] However, only a few studies reported the experience of patients with ABI during RTW [10–13]; another study investigated the experiences of employer specialists, without actively involving the patients themselves.[14] Hence, it remains unclear what patients regard as possible solutions when RTW is problematic. According to the patients with ABI, a supportive employer with a positive approach facilitates RTW, while lack of knowledge and support from employers and colleagues were mentioned as important limiting factors.[12,13] Not only the patient but also the employer seems to have an important role to play in achieving successful RTW. Nevertheless, research on the employer’s perspective on RTW of patients with ABI is scarce.[15] In order to fill this gap, the present study has therefore been designed to investigate the factors experienced as barriers to or facilitators of RTW, or as solutions to RTW-problems, according to both patients with ABI and employers.

**Methods**

The study was designed to be qualitative and conducted in accordance with the consolidated criteria for reporting qualitative research (COREQ).[16] Patients and employers participated in individual, semi-structured interviews. These interviews were conducted to explore their views on the barriers to or facilitators of RTW after ABI and on possible solutions to problems encountered in this process. Sampling was guided by the research question (i.e., what are barriers to, facilitators of RTW and possible solutions to RTW-problems?). Patients and employers were unrelated.

**Ethics**

The research was conducted in accordance with the declaration of Helsinki.[17] The research proposal was submitted to, and approved by the Medical Ethical Committee of the Academic Medical Center, that judged a comprehensive evaluation was not required since this study was not subject to the Medical Research Involving Human Subjects Act (Reference number W13_043# 13.17.0057).

**Patients**

Patients were eligible to take part in the study if they had non-progressive ABI, were of working age (18–65 years), had a paid job at the moment of injury, had an adequate command of Dutch and were willing to participate. They were recruited through Dutch ABI-patients associations. Representatives and experts from these associations posted information about the study on their website or in magazines, and also distributed flyers containing written information about the study to potential participants in their regional networks. Dutch rehabilitation centers were also asked to hand out such flyers to their patients. The recruitment procedure was designed to collect a heterogeneous sample of patients with different work settings from different geographic regions in the Netherlands. When patients indicated that they were interested, the first author (BDC) contacted them by telephone or by e-mail to clarify the aims and procedures of the study. All interested patients received detailed written information about the study and an informed consent form. The research team decided to plan interviews with the first twelve consecutive patients who met the inclusion criteria and agreed to participate, had signed the informed consent form and were enrolled in the study. Patients were interviewed sequentially until no new facts appeared regarding facilitators of, barriers to RTW and solutions to RTW-problems according to the preliminary analysis of the previous interviews; it was concluded at this point that data saturation had been reached.

**Employers**

Employers – that is, directors, line managers, supervisors, HR managers and the like who were closely involved in the RTW-process of at least one patient with ABI – were eligible to participate in the study. Initial attempts to recruit employers by contacting various companies were unsuccessful. The research team therefore decided to approach all fifteen employers who were nominated for awards by the Dutch Brain Foundation between 2010 and 2012. These annual awards were established for employers demonstrating sustained and outstanding efforts aimed at helping patients with any type of brain damage to RTW. According to the website of the Dutch Brain Foundation, eleven of the fifteen nominees (including those who actually won the awards) had at least one patient with non-progressive ABI among their employees. These eleven employers were contacted and informed about the aims of the study. If they were interested, they received further written information. Those employers who were willing to participate were sent an informed consent form, which was filled in and signed before the interview took place. The interviews were continued until it was concluded that no new information was being obtained regarding facilitators of, barriers to RTW and solutions to RTW-problems according to the preliminary analysis of the previous interviews and thus the data saturation had been reached.

**Interviews**

Participants were fully informed about all aspects of the study, including the fact that all information collected was treated in strict confidence, before the start of the interview. The first author, who is an experienced insurance physician trained in qualitative research on ABI and RTW, held face-to-face semi-structured interviews with all patients and employers. She had no contact with the participants before the start of the study. Participants were interviewed once, with no one else present, at a time and location that suited them. All interviews were audio-recorded with the consent of the participants. The research team developed one interview structure for patients and another for employers. Interviews were based on the use of topic lists derived from the study objectives. The topic lists for all participants contained items concerning demographic characteristics; work-related issues, such as patients’ former and current employment status; barriers to and facilitators of RTW and solutions to RTW-problems. In addition, patients were asked about their medical history and the treatment they had received. The interview was guided by open-ended questions, developed through discussion with the research team. Typical questions addressed to patients included: "What did you experience as a barrier to your RTW?" "What impact did this have on your own RTW?" and "What approach was taken to deal with this problem?" The questions for employers included: "Which factors, in your opinion, enabled your employee to RTW?" "Which factors do you believe made it more difficult for your employee to RTW?" and "In retrospect, what steps were taken to resolve the problems that arose during your employee's RTW?" Both patients and employers were encouraged to take active part in the discussion and to speak freely about any matters they saw as key RTW-issues. The interviewer summarized the interviewees’ replies and presented the
summaries to them, in order to give them an opportunity to clear up any misunderstandings.

**Data analysis**

All audio-recorded interviews were transcribed verbatim. The transcripts were read and reread by the first two authors (BDC and MS) to obtain an overall impression of their content. MAXQDA qualitative data analysis software (Verbi GmbH Marburg, Germany) was used to facilitate data management.

Interview data obtained from patients and employers were analyzed separately. The first author (BDC) initially coded the first patient interview line by line and discussed the selected codes with the research team (MS, HW, and MFD) until consensus was reached. The coding process involved identifying words or phrases representing the basic meaning of the text as closely as possible. The first two authors (BDC and MS) then both coded the next patient interviews separately. The codes initially identified were subsequently grouped under three headings: facilitators, barriers, and solutions to RTW-problems as perceived by patients. The first two authors then compared each other's coding and inconsistencies were discussed until consensus was reached. The codes were also discussed with the whole research team until disagreements concerning the codes and their grouping had been resolved. The interviews with employers were analyzed in the same way.

**Results**

Data saturation was achieved after ten of the twelve planned patient interviews had been performed. All interviews were held in May 2013; three at the patient's home and seven at the workplace. The mean duration was 63 min (range 44–87).

Nine of the eleven eligible employers were willing to participate. Interviews were also held in May 2013; all except one at the workplace. They lasted on average 38 min (range 28–51). In this case, data saturation was reached after seven interviews.

**Characteristics of participants**

Participant characteristics are presented in Tables 1 and 2. Five patients were male and five were female. Their mean age was 47 years (range 34–63). In two patients ABI was caused by a traumatic event; seven sustained non-traumatic ABI and one suffered two ABIs. The mean time since ABI was 10 years (range 2–32). Eight patients were highly educated. Before their injury, the patients had worked in business, science, health, and teaching. Six had a full-time job, three worked part-time and one was at school. After ABI, five patients returned to their former employer with permanent job adaptations. Two moved to a different type of work, and one failed to RTW. One patient initially returned to work and then retired.

The employers were all middle-aged; four were male and three were female. Three of them worked as a line manager, one as a director, another as a supervisor, and two were HR managers. They had worked in a wide variety of different sectors – including the police, a hospital, a school, a factory, and a national sports federation – for several years. The organization size ranged from 30 to 11 000 employees, with a mean of 2500 employees.

**Interview findings**

Patients and employers mentioned a large number of facilitators, barriers and solutions to RTW-problems. The research team grouped these into the following categories: (1) condition-related, (2) patient-related, (3) work-related, (4) environment-related, and (5) guidance/coaching/support. Furthermore, a distinction was made between effectuated solutions (which had been put into practice) and hypothetical solutions (which had not). All facilitators, barriers and solutions are presented in detail in the Supplementary online material. Some are outlined below, along with quotations to illustrate them.

**Factors experienced as facilitators of RTW according to patients and employers**

**Patient-related**

Patients and employers identified several factors facilitating RTW, such as the patient’s drive. Patients and employers agreed that good job performance prior to ABI facilitated RTW. One employer stressed the importance of being a good team worker.

... as far as I could see, he really fitted into the team ... He did a lot to promote social cohesion (employer 5).

**Table 1.** Patient characteristics (gender, age, time since ABI, cause ABI, work status before/after ABI).

| Patient | Gender | Age when interviewed<sup>a</sup> | Time since ABI when interviewed<sup>a</sup> | Cause ABI<sup>b</sup> | Work status before ABI<sup>c</sup> | Work status after ABI<sup>c</sup> |
|---------|--------|-------------------------------|----------------------------------|------------------|-----------------------------|----------------------------------|
| 1       | Female | 63                            | 5                                | NT               | Part-time                   | Part-time                         |
| 2       | Female | 48                            | 18:6                             | T and NT         | Part-time                   | Part-time                         |
| 3       | Male   | 36                            | 5                                | NT               | Full-time                   | Part-time                         |
| 4       | Male   | 47                            | 5                                | T                | Full-time                   | –                                 |
| 5       | Male   | 40                            | 32                               | NT               | –                           | Part-time                         |
| 6       | Female | 34                            | 2                                | NT               | Full-time                   | Full-time                         |
| 7       | Male   | 50                            | 15                               | NT               | Full-time                   | Full-time                         |
| 8       | Female | 37                            | 2                                | NT               | Full-time                   | Part-time                         |
| 9       | Female | 58                            | 12                               | NT               | Part-time                   | Part-time                         |
| 10      | Male   | 56                            | 3                                | NT               | Full-time                   | Part-time                         |

<sup>a</sup>In years.

<sup>b</sup>Non-Traumatic (NT), Traumatic (T).

<sup>c</sup>Part-time = <38, full-time = ≥38.

**Table 2.** Employer characteristics (gender, company, number of employees, position).

| Employer | Gender | Company                | Number of employees | Position     |
|----------|--------|------------------------|---------------------|--------------|
| 1        | Male   | Town hall              | 1900                | Supervisor   |
| 2        | Female | Academic hospital      | 11,000              | Line manager |
| 3        | Female | National Sports Federation | 29                | HR manager   |
| 4        | Male   | Police office          | 1230                | Line manager |
| 5        | Male   | School (13,836 students) | 2965               | Director     |
| 6        | Male   | School (1400 students) | 140                 | Line manager |
| 7        | Female | Factory                | 240                 | HR manager   |
Only patients mentioned the importance of active involvement in their own RTW-process:

...I did it my way ... that was very important to me (patient 1).

Work-related
Employers emphasized the importance of ensuring that RTW did not lead to financial loss for the company.

...After all, in the final analysis we're here to make profits (employer 7).

Employers also referred to their own role in helping patients to RTW, and noted the importance of their willingness to support the patient. It helped if they really wanted the patient back at work. Patients confirmed this from their own perspective. In addition, both patients and employers noted that if an employer had sufficient knowledge of ABI and how it might affect the ability to work, this definitely facilitated RTW.

One patient mentioned his employer allowed him to work at his own pace.

Environment-related
Both patients and employers underlined the importance of support from the partner, whose observation of the patient's functioning at home helped to reset goals during the RTW-process.

Guidance/coaching/support
Patients and employers both mentioned that professional support facilitated RTW.

... the labor expert had already prepared me to play my role (employer 2).

Patients appreciated contact with fellow sufferers, they learned from their experience.

...All I can say is that I learned an awful lot from it (patient 9).

Factors experienced as barriers to RTW according to patients and employers

Condition-related
Patients reported feeling vulnerable during RTW due to invisible disabilities such as fatigue or cognitive problems. Employers reported observing similar problems.

Patients' inability to explain these disabilities was mentioned as a problem in its own right.

I didn't have a clear picture of what was going on at that time ... it was impossible to explain the problem to anyone else (patient 6).

Patients and employers mentioned fatigue as an important barrier to RTW in this context.

... my colleagues told me, 'just go home, old chap. There's no point in staying on' ... I just couldn't handle it: I was so tired! (patient 4).

Patient-related
Employers noted that if the patient was too driven, for example by the need to maintain financial security, the resulting stress might threaten successful RTW.

"... 'look, I need the money ... what if I won't be able to work at all anymore ... who will look after me then?' (employer 3 citing patient).

Work-related
Patients and employers both noted that line managers' lack of knowledge of sick leave, and company reorganization, were barriers to RTW. One employer added that reorganization led a patient to be placed in an unsuitable job.

As a result of the reorganization, he was ... placed in the administration department ... Well, if there's one job ... he's not good at, that's administration (employer 1).

Patients stated that many work-related factors, such as a gradual increase in workload, impeded successful RTW.

... the workload was gradually increased, and then at a given moment you realize that you simply can't cope any more (patient 8).

Both patients and employers mentioned sensory overload at the workplace as major barriers to RTW.

... if you have to work in an open-plan office like this, with continuous murmur, normal functioning is dramatically hindered. (patient 2).

Environment-related
Patients and employers mentioned pressures at the patient's home or people claiming a patient's time as barriers to RTW.

... the home situation was already so burdensome ... it could not be combined with work (patient 4).

Guidance/coaching/support
Patients complained that they did not receive sufficient information about the consequences of ABI from the physicians who treated them. They had no clear picture of their limitations when they returned to work, which led to a feeling of helplessness. Patients further noted that occupational and insurance physicians had insufficient knowledge of ABI, which slowed down the RTW-process in their opinion. Several patients needed to know more about the relevant regulations, and found it difficult to access the appropriate sources of information.

... The people I need to call on for advice ... are hidden away behind the almost impenetrable maze of options set up by call centers (patient 3).

Employers mentioned no barriers in this context.

Effectuated solutions according to patients and employers

Condition-related
Contact with fellow sufferers and work samples helped patients to gain a better understanding of the limitations caused by their ABI.

Patient-related
Both patients and employers mentioned that RTW is facilitated if the patient sets limits.

... and then I started thinking... there's no point in overloading myself... so I told ...I don't want to work more than ... 5 and a half hours a day, 5 days a week (patient 10).

One patient benefited from training on personal effectiveness.

... what really helped me was ... a training course ... where I worked on my own personal effectiveness (patient 5).

Work-related
Patients and employers both mentioned focusing on abilities as a crucial initial step in the RTW-process.

But the most important thing for me was ... making up my own mind about what I was able to do (employer 2).

Both parties mentioned the importance of workspace adaptations.

... for example, we had to convert a soundproofed studio into an office with low external noise levels (employer 6).
Patients reported that colleagues drove them to and from work if they had problems driving themselves.

I get taken to work and brought home … And I’ve never had anyone at all complain about the inconvenience it caused them (patient 7).

Environment-related
One of the patients arranged to have home help to perform domestic tasks as she felt too tired to do herself.

Guidance/coaching/support
Both patients and employers mentioned cases where professional assistance was called in during RTW, as a sounding board for the employer and to act as a coach for the patient.

Hypothetical solutions according to patients and employers
Patients and employers also listed a number of promising solutions that had not already been put into practice in the experience of the interviewee in question. Patients mentioned such possibilities in all categories; these suggestions included engaging professional assistance during the RTW-process.

… to provide supervision and support… very important … to do that on a professional basis (patient 9).

The hypothetical solutions recommended by employers were only work-related, and involved professional support if appropriate. One employer mentioned the importance of emphasis on abilities instead of limitations during RTW.

… you need to see what he can do, and put him in a job where he can use those skills (employer 1).

Discussion
The purpose of this study was to investigate the factors experienced by patients with ABI and their employers as facilitators of or barriers to RTW, and as possible solutions to RTW-problems. Facilitators, barriers, and solutions to RTW-problems according to patients and employers were grouped into subcategories: (1) condition-related, (2) patient-related, (3) work-related, (4) environment-related, and (5) guidance/coaching/support. The solutions were categorized into effectuated solutions (which had been put into practice) and hypothetical solutions (which had not).

Both patients and employers identified patient-related factors, such as good pre-injury job performance and work-related factors, such as supportive colleagues (e.g., taking over patient’s duties, showing understanding, providing emotional support) that facilitate RTW. As far as barriers to RTW are concerned, both patients and employers underlined the importance of work-related factors such as sensory overload at the workplace and condition-related factors like fatigue. Patients mentioned that a lack of guidance and support could hinder RTW, but employers did not. Most of the solutions mentioned by patients and employers were work-related, supplemented if necessary by professional assistance. Patients also listed other essential solutions such as understanding and acceptance of the limitations of ABI.

Comparison with other studies
An inability to ignore sensory overload at the workplace was commonly perceived as a barrier to RTW by the patients and employers participating in the present study. This problem seems to be particularly relevant to patients with ABI, as they often have problems with attention and concentration. Reduction of sensory overload might therefore make a substantial contribution to RTW of patients with ABI.

Some of the results of this study are in line with those of prior qualitative studies on RTW of patients with other chronic diseases. Patients and employers in the present study underlined the importance of invisible limitations such as cognitive disabilities and fatigue as barriers to RTW. These experiences are consistent with those of patients with cancer, who reported that fatigue and cognitive problems impeded work functioning for a long-time after cancer diagnosis and treatment.

Cognitive problems were dealt with by reducing the amount of tasks to be performed in a working day. Fatigue could be combated by reducing working hours or working from home; in line with the solutions in this study.

Patients in this study reported a lack of understanding by employers as a barrier to RTW, in agreement with the results of other qualitative studies concerning workers with back pain [21] and cancer. Cancer patients suggested that this lack of understanding might be due to the fact that their limitations were not visible to the naked eye, in line with the comments of the patients and employers in the present study. Cancer patients mentioned that provision of information on such topics as fluctuations in fatigue level might be helpful. Similarly, calling in the assistance of a professional such as a rehabilitation specialist was seen as a valuable solution by patients and employers in the present study. This is consistent with the findings of a previous investigation, where the rehabilitation professional provides information on measures that might facilitate RTW of patients with ABI.

The results were promising: the rehabilitation professionals, patients, employers, and occupational physicians agreed that this approach did facilitate RTW of patients with ABI.

Methodological considerations
The design of this qualitative study allowed a better understanding of the complex RTW-process by exploring the experience of patients and employers – the most important stakeholders in this process – through semi-structured interviews. Analysis of the extensive overview obtained in this way may point out ways of improving RTW of patients with ABI.

The patients in this study were self-selected; they proactively indicated that they were interested in participating. This may have yielded a population consisting of individuals who were highly motivated to RTW. The patients in this study suggested a number of solutions to RTW-problems, such as emphasis on abilities that may be applicable to patients with ABI in general. Further research building on the results of this study may make it possible to develop procedures that will be helpful in the daily practice of assisting patients to RTW after ABI.

In line with previous reports it was difficult to recruit employers for the present study; they may have been reluctant to participate due to considerations of business confidentiality, and because they did not wish to have their methods of managing employees’ RTW analyzed in detail by a third party. The research team therefore decided to recruit employers who were motivated to participate because they had been nominated for an award recognizing outstanding performance in the RTW of patients with ABI. This resulted in a sample of nine employers. Data saturation was reached after seven consecutive interviews: no new facts appeared regarding facilitators of or barriers to RTW and solutions to RTW-problems. The analysis of unsuccessful attempts to help
such patients to RTW might have yielded useful additional insights. However, the strength of the present study is that the solutions reported as having been adopted did lead to success in the RTW-process. This makes them valuable examples of proven practice in RTW of patients with ABI that could be applied by other organizations.

**Implications**

Employers as well as patients are intimately involved in RTW of patients with ABI. Patients and employers need one another, and both their perspectives need to be taken into account. Other authors have similarly demonstrated the importance of employer involvement during RTW of cancer patients.[23,24] However, the communication between the stakeholders in the RTW-process is still often inadequate.[25] Patients in the present study mentioned having problems understanding and accepting the limitations they were subject to as a result of their ABI, which hindered their communication with the employer and consequently RTW. Patients gained a better understanding of their limitations through contact with fellow sufferers. This enabled them to discuss their limitations with their employers and to propose limits on their own activities. Employers saw such input as helpful in facilitating their employees’ RTW.

Employers in the present study, in their turn, facilitated RTW of patients with ABI in their employment by restructuring the workplace to take the patients’ strengths into account, and mentioned that professional assistance (from a rehabilitation specialist, occupational physician, labor expert, re-integration agency or the like) could be crucial in this context.

Patients in this study noted the importance of self-involvement in the RTW-process, which can be facilitated if all stakeholders work together to promote patient-centred care through shared decision-making. In line with this, RTW of patients with ABI may be facilitated in the future if all professionals involved in the RTW-process are aware of the perspectives reported in this study and implement them successfully in their daily practice.

**Conclusions**

Patients and employers identified patient-related factors, such as good pre-injury job performance and work-related factors, such as supportive colleagues that could facilitate RTW. As barriers to RTW both patients and employers underlined the importance of work-related factors, such as sensory overload at the workplace and condition-related factors, such as fatigue. Patients mentioned that a lack of guidance and support could hinder RTW. Most of the solutions mentioned by patients and employers were work-related, supplemented if necessary by professional assistance. Patients also emphasized the need for understanding and acceptance of the limitations resulting from ABI in any RTW-solution.

**Disclosure statement**

The authors report no declarations of interest.

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