

Background

It is widely recognised that education for spinal cord injured (SCI) patients is essential for optimal health, wellbeing and independence (Burkell et al., 2006). Family members consistently report that timely information is one of their most important needs, particularly in the early stages following SCI (Foster et al., 2005). Due to long waiting lists for rehabilitation in countries including Ireland, the UK, Italy, and Canada, SCI patients often spend months in acute care (New et al., 2013). However, little is known of the information needs of SCI patients in acute care before rehabilitation, nor on the information needs of family members in general.

Methodology

We conducted semi-structured interviews with seven traumatic SCI patients (ranging from L3 incomplete to C5 complete) and six family members (a daughter, mother, father, husband, wife and brother).

Patient participants spent an average of **155 days awaiting rehabilitation**, an average of 130 of which were spent in **non-specialist acute care**.

Interviews were transcribed verbatim, data was analysed using reflexive thematic analysis. Five themes were generated.

1. "You were lying in limbo and you knew nothing"

All patients and family members had significant unmet information needs in acute care:

"I knew absolutely nothing. I didn't know what was happening to my body" - Susan, patient

Being in non-specialised acute care significantly limited patients' and family members' access to information, which often impacted their mental health and ability to cope. Participants reported that staff in non-specialist acute care typically had limited knowledge of SCI:

"The nurses don't really know about the spinal cord, they never told me about it." - Carlos, patient

Non-specialised hospitals and nursing homes were also under-resourced and under-staffed, which further limited access to information.

"They're all so busy and short of staff. They're doing their best, but not as much as a patient needs." – Amir, patient

As a result, participants typically relied on "hearsay" and untrustworthy online information. Results indicate that providing specialised care to SCI patients throughout the acute phase would improve patients' and family members' access to information during this time.

2. "You'll never walk again" is not enough

Patients and family members reported needing detailed information regarding the patient's potential recovery of movement, function and independence; the management of secondary conditions including pressure relief, self-catheterisation, bowel care and autonomic dysreflexia; and what to expect in rehabilitation. Patients also wished they had received information about maintaining strength and practicing independence while in acute care:

"I mean I was a ball of jelly when I came, I hadn't a muscle [...] If I had realised the strength you needed in your upper body I would have worked for six months, diligently at it" - Barbara, patient

3. "Just explain it to me, in an easy way that I can understand"

Participants reported that information was often communicated by healthcare professionals "in a skip-over fashion", during acute care:

"They would mention I had a spinal injury [...] But I didn't really realize the seriousness of it, and they didn't really explain it to me." - Barbara, patient

Healthcare providers often used medical jargon which participants did not understand, resulting in confusion and distress:

"They were giving me things like T5 or T6, but I hadn't a clue what that means." - Peter, husband

Participants stressed the need for healthcare providers' openness and honesty, as well as empathy, sensitivity and support when sharing information.

4. "It was going in one ear and out the other"

Many participants described having difficulty absorbing information in the early stages post-injury. The effects of painkillers, shock, or having received a concurrent brain injury affected many patients' ability to remember their initial conversations with their doctor. As a result, family members were often solely responsible for remembering information provided by the spinal injuries unit. Each participant also had a different trajectory of acceptance, which impacted their readiness to learn SCI-related information:

"It didn't register, because always at the back of my mind I thought 'it doesn't matter, I'll be going to rehab and I'll be walking home.'" - Barbara, patient

Results indicate that even when patients or family members appear to immediately understand, they may need information to be repeated, reinforced and clarified. Information should also be provided in a variety of formats, including written and video.

5. "Hope" not "false hope"

Participants reported that healthcare providers should promote realistic hope for SCI patients and family members, even in the absence of neurological recovery, by focusing on what the patient is still capable of while being honest about their prognosis:

"So I can understand that with spinal injury the world does not end. It gives the idea that I'm going somewhere, there's at least hope. So it helps us be strong." - Amir, patient

However many healthcare providers in acute care focused solely on the negative aspects of SCI when talking to patients and family members:

"They really try hard to squash the hope, completely kill it [...] And that was wrong. And mentally that was very hard." - Jessica, daughter

Peer support was highly valued by patients and family members during this time, as hearing about their lives gave them hope for the future.