

EDITORIAL

The emerging patient-led revolution of early colostomy following spinal cord injury

In a world where there is a growing focus on and demand for patient-focused care, there remain many situations where patients continue to struggle to be heard. This editorial will explore an example of where patients are making their voices heard, questioning the status quo and changing professional attitudes to a potentially life-changing aspect of their long-term care. Is this evidence of a patient-led challenge to the scientific knowledge and tradition of the day or a gradual process of transition towards a new model bowel of care for people living with spinal cord injury (SCI)?

Sustaining a Spinal Cord Injury (SCI) is life-changing in many ways and affects a significant number of people. Information from UK databases suggests incidence to be 18-19 cases per million population, which equates to approximately 1200 new cases each year, with at least 40,000 people in the UK living with SCI (McDaid et al., 2019). The profile of those sustaining SCI has changed over recent decades. Approximately three times as many men as women continue to be affected, but SCI increasingly affects older people and can be due to falls (46%), as well as road traffic accidents (40%), violence and sporting injuries (4%), and other non-traumatic causes (Hasler et al., 2011). Incidence and causation of SCI vary between countries and recording inconsistencies impact on the quality of data available.

An often-hidden effect of sustaining a SCI is the disruption it causes to bowel function. To overcome this, healthcare professionals have produced physiologically focused bowel management guidelines (MASCIP, 2021). Recent research evidence suggests that these guidelines fail to meet the needs of wider personhood for this group of patients (Boucher, 2022). Patients are no longer willing to accept care that does not meet their needs, and a patient-led revolution may be unfolding that is driving healthcare professionals to review and change their professional perspectives.

Following a SCI, damage to the nerves which supply the bowel can lead to Neurogenic Bowel Dysfunction (NBD) (MASCIP, 2021). This results in slower colonic transport of stool, absent awareness of a full rectum and an inability to control the muscles which expel stool from the body. With this reduction or absence in necessary bowel function, healthcare professionals have developed interventions aimed at achieving regular bowel emptying and maintaining continence. This widely used and internationally agreed guidance advocates for the use of 'least invasive' interventions as the mainstay of bowel function management. These interventions include manipulation of diet, use of medication, the development of routine and methods of manually removing stool from the rectum such as

digital stimulation and digital removal of faeces. The guidelines go on to suggest that if these least invasive methods do not produce satisfactory bowel function, a progression may be made through interventions which are considered increasingly more invasive. The final and most invasive option to be considered is stoma formation. The type of stoma is commonly a colostomy, which is a surgically created opening in the abdomen through which the colon is diverted and stool then exits into an attached disposable pouch.

Close examination of these guidelines reveals that they are based on weak evidence and developed by healthcare professionals using consensus methods but with limited involvement of those they are designed to support. The development of guidelines with a poor evidence-base may help to account for a deviation in accepted practice which has been documented as occurring in one spinal injury rehabilitation centre in the UK (Boucher, 2022). In this centre, instead of acquiescing to the use of least invasive methods of bowel management, individuals earlier in the trajectory of their SCI have been observed, in increasing numbers, to request the most invasive option of colostomy in the early weeks and months following their injury. Such requests do not fit comfortably alongside professionally constructed guidelines which dictate the use of least invasive interventions with increasingly invasive interventions used as a last resort.

When exploring the evidence on bowel management following a SCI, there is much research confirming the widely held view that colostomy formation should only be used as a last resort when all other options have failed to produce satisfactory bowel management. These same studies, however, tend to report a pervasive satisfaction with colostomy formation, with patients describing it as a quicker, easier and more reliable intervention. Many studies go on to describe those with SCI as reporting a wish to have known about and undergone colostomy formation much sooner following their injury. With this finding repeatedly and consistently documented over the years, the question must be posed as to why further research has not been performed to investigate why those with SCI would like to have had an earlier colostomy and why practice and guidelines have not been developed and progressed in the light of this finding?

With healthcare professionals apparently immobilised and unable to advance in their thinking and practice, it has been left to those who require bowel interventions following a SCI to overturn traditional models and innovate a new way of perceiving body management. Listening to patients' perspectives, disparities in

notions of 'invasiveness' are observed between patients and those described by professionals in guidelines. Patients inversely find manual removal of stool to be an invasive procedure and colostomy to be less invasive. It can further be understood that colostomy is used as a 'means to an end' of achieving important life goals. Methods of body management are desired which facilitate reintegration into their former lives of family, work and society as far as is possible, thus reducing the number of barriers they perceive to be disabling.

A scientific revolution is said to occur when increasing numbers of anomalies occur which are at odds with tradition-bound activity based on accepted scientific knowledge (Kuhn, 1996). Prior knowledge and theory must be reconstructed and a new question asked. The anomaly of the increasing and earlier choice to have a colostomy following SCI is currently at odds with accepted professional knowledge and wisdom which dictates reliance on 'least invasive' methods of body management. New knowledge and theory gained from listening to insider perspectives of those with SCI must be used to appraise and re-write traditional bowel management guidance. The question then changes from 'how can normal bowel function be maintained following SCI' to 'how can bowel function best be managed to achieve the life goals of those with SCI'.

Scientific revolution or not, new research in this area has revealed that professional development has been limited by clinicians placing too much focus on physiological management rather than a holistic understanding of a person's lived experience and life course. Those with SCI are observed to increasingly make choices which show this to be a reductionist perspective, which cannot account for their wider life worlds and life goals. The question is, will professionals be resistors or facilitators of this unfolding demand for greater choice in how people with SCI manage their own bodies?

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