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Patients’ experience of living with faecal incontinence

M. Wilson
Westwood Hospital, East Riding of Yorkshire Primary Care Trust, Beverley, Humberside, UK

Abstract
This grounded theory study investigates what it is like to live with faecal incontinence (FI). In-depth guided interviews were conducted with 22 community-dwelling adults between April 2002 and September 2003. There was also a 5-year follow-up study to find out how participants were coping, in which 11 individuals took part. Subjects described their fears and anxieties at the initial interview, and many reported feeling stigmatized, socially unacceptable and alone. Some had become reclusive and others were very reliant on close family members. Using framework analysis, the participants were classed as either overwhelmed, accommodating to FI or approaching mastery on a dynamic continuum. When they were interviewed 5 years later, most subjects were approaching mastery. These tended to be people who had had the problem for many years and used proactive management for the condition (i.e. trial and error). They displayed resilience, which can be learned and developed through experience, and includes self-esteem, self-confidence and feelings of control. By this stage, the individual often feels able to act as a role model for those who are less advanced in their adaptation to their problem. Having a supportive partner also plays a part in moving up the escarpment towards mastery at the top. Heath professionals need to be aware that individuals require different interventions at different stages of the continuum, and they can help the transition from being overwhelmed to mastery by offering therapeutic, pharmacological or practical help.

Keywords: adaptation, faecal incontinence, mastery, resilience.

Dr Mary Wilson is an advanced practitioner for bladder and bowel health who works for East Riding of Yorkshire NHS Primary Care Trust. Based at Westwood Hospital, she covers the Bridlington and Wolds communities as part of a specialist team of three nurses with a healthcare assistant. Mary won the public award for her outstanding care for patients in the 2010 East Riding of Yorkshire NHS Star Awards. Her presentation is available online at: http://www.acpwh.org.uk/docs/conf/2010/MaryWilson.pdf

Correspondence: Dr Mary Wilson, Advanced Practitioner for Bladder and Bowel Health, Westwood Hospital, East Riding of Yorkshire Primary Care Trust, Woodlands, Beverley, Humberside HU17 8BU, UK (e-mail: mary.wilson@erhtsp.nhs.uk).

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