

ACPWH CONFERENCE 2010

Patients' experience of living with faecal incontinence

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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. Health 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.

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Her presentation is available online at: <http://www.acpwh.org.uk/docs/conf/2010/MaryWilson.pdf>

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