

# EFFECT OF AN EMPOWERMENT PROGRAM FOR PEDIATRIC PATIENTS WITH DISORDERS OF DEFECATION AND THEIR FAMILIES

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July 2015

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**Objective:** To investigate the effect of an empowerment program for patients with disorders of defecation and their families

**Methods:** Twenty-seven pediatric patients aged 1-14 years with a defecation disorder and their mothers participated in an empowerment program consisting of two parts (one for mothers and one for patients) designed to help patients smoothly transition to self-care. The part for mothers mainly provided psychological support and information, while the part for patients aimed to increase patients' understanding of defecation disorders and help them attain self-care skills.

**Ethical considerations:** The study was reviewed and approved by the ethics committees of both the university and the university hospital where data was collected.

**Results:** Twelve patients had anorectal malformation, 11 had Hirschsprung's disease, 2 had cloacal malformation, 1 had Currarino syndrome, and 1 had constipation. A series of patient-mother-researcher sessions (mean duration, each 30-45 minutes) were given over a period of 1-6 months, depending on the patient's age and individual situation.

Effects of intervention were seen in seven areas of support: (1) attainment of patients' independence in defecating; (2) introduction of forcible defecation; (3) identification of developmental disorders and provision of appropriate support; (4) increasing patients' understanding of defecation disorders to promote independence; (5) preparation of a social environment for patients' development; (6) explanation of the disease and sex education; and (7) providing support for prevention of school refusal. For area (4), the following specific steps were taken in the following order: patients were interviewed to uncover their understanding of diseases, feelings about the current situation, and future intentions; it was made clear to patients that their mothers and nurses were "supporters" for helping them do their best; patients were encouraged to promise to do what they could (e.g., taking regularly scheduled toilet breaks and recording daily defecation status); their number of outpatient visits was increased to once a month; their awareness of diseases was confirmed by quizzing on the names and brief description of diseases; and lastly they were reminded of their promises, thereby increasing self-care activities (e.g. trying hard to defecate every morning, changing out of wet underwear, washing dirty underwear by themselves). Whether patients were enjoying school was confirmed by asking for friends' names and playtime activities. A third-year primary school patient became able to self-administer an enema, and a fifth-year primary school patient talked about defecation disorders in front of the class during a lesson on diseases and illness.

**Discussion:** This study revealed that it is important for pediatric patients to understand their own diseases and conditions regarding defecation. It was also suggested that good nursing for outpatients as well as establishment of the system and network necessary for continuous provision of nursing care are needed.