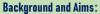
QUALITY OF LIFE OF PATIENTS WITH COLOSTOMY OR ILEOSTOMY IN HOSPITAL AT HOME:

RESULTS OF THE STOM'HAH STUDY



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A quality of life study carried out in 2019 in our hospital at home (HAH) showed that ostomates were among the most impaired of our patients.

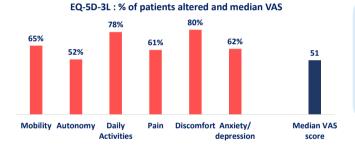
We decided then to perform a specific study on patients with ileo or colostomy, in order to assess their quality of life and to better understand their specific difficulties.

Methods:

- A questionnaire was sent by e-mail to the patients with a colostomy or an ileostomy, aged more than 18, and treated in our HAH in the past six months (258 questionnaires sent)
- The questionnaire included the validated EQ-5D-3L quality of life scale and a list of 28 specific questions (about wound and materials, general signs, psychology, social relationships...) created by our group of stoma therapists.

Characteristics of patients:

- N = 58 patients (36 colos; 22 ileos)
- Men 45 % / Women 55 %
- Mean age 70 years (39 92)
- 70 % cancer
- · 33 % transient ostomies
- Median duration of stoma: 5,44 months



Qualitative questionnaire:

- The device is comfortable for 70% of patients
- 81 % are not independent in their ostomy care
- 64% are afraid of the bag coming loose
- 31% have frequent leaks
- 38% think their bag smells bad
- 67% have problems choosing their clothes
- 77% are afraid of meeting new people
- 73% never practice outdoor leisure activities

2 dominant groups of patients:

- Recent ostomy, often transient, with good health status
 → functional problems dominant, with strong impact on daily life and social interactions
- Older ostomy with major alteration of health status
 → QOL problems more linked to the general status than the ostomy, most often better managed and accepted

Actions

- Learn staff to better identify typology of patients and consequent needs: don't focus only on the wound!
- Offer adapted support at home: psychologist, dietician, stoma therapist, but also palliative care team if appropriate
- Offer education and support to the caregiver, often at the frontline
- Encourage social activities and offer well-being services (art-therapy; socio-aesthetics; massage...)

Conclusions:

Patients with a stoma have a significantly reduced quality of life. The care must therefore be holistic (psychologist, dietician, social worker, socio aesthetics, mobile palliative care team,...) and not only focused on wound and device problems. Actions are underway to meet the needs of patients, but also of family caregivers, who are often heavily involved.

A qualitative study is being considered to clarify what could help patients to get off the house and develop their social interactions.