Developing a Stoma Acceptance Questionnaire to improve motivation to adhere to enterostoma self-care

A. BAGNASCO [1], R. WATSON [2], M. ZANINI [1], G. CATANIA [1], G. ALEO [1], L. SASSO [1]

[1] Department of Health Sciences Department, University of Genoa, Italy; [2] Faculty of Health and Social Care, University of Hull, UK

Keywords

Summary

Introduction. *In stoma care, patient education is often weak in terms of improving patients' level of acceptance of living with a stoma. Self-care educational interventions in enterostomal patients, which according to Orem's Theory should take into account these patients' specific needs, require instruments that measure patients' stoma acceptance to improve motivation based on the resumption of activities they used to carry out before having a stoma.*

The aim of the study was to develop an instrument that measures the level of stoma acceptance to improve motivation to adhere to enterostoma self-care.

Methods. *Aspects that improve stoma acceptance and consequently motivation to adhere to enterostoma self-care were identified through 10 focus groups. In the focus groups, the motivation indicators were grouped, categorised and results entered into a Stoma Acceptance Questionnaire (SAQ). The SAQ was then piloted with 104 enterostomal patients from three general hospitals.*

To assess the construct validity of the SAQ, Mokken Scaling was used to explore the latent structure of the SAQ. Mokken scaling is a non-parametric method that falls under the umbrella of methods described as item response theories (IRT).

Results. *The theme "Living with a stoma"; "Autonomy"; "Support"; "Ability to deal with stoma", plus a common underlying theme: "Stoma acceptance" were disussed by the Focus Groups. The experts identified the items of the (SAQ) through these themes. Mokken Scaling identified the "resumption of enterostomal patients' normal activities" as a measure of stoma acceptance, thus confirming the construct validity of the SAQ.*

Conclusions. *The tool proposed affords a pioneering example of how this gap can be bridged. Indeed, the SAQ could enable nurses adopting a standardized approach for the assessment of enterostomal patients' motivation to resume their normal activities and identify needs linked to this. The SAQ could also be used to measure the effectiveness of psychosocial and educational interventions aimed at improving stoma acceptance.*

Introduction

It is known that quality of life of stoma patients is negatively influenced by stoma, and the patients' positive adjustment of their perception is possible only through acceptance of the stoma [1]. However, there is evidence that nursing documentation is often weak, and in particular it lacks a consistent and standardized approach to assessing the educational needs of the enterostomal patient linked to stoma acceptance [2-4]. The documentation of enterostomal patients' educational needs could be improved by using a structured approach employing appropriate instruments. Several tools are available, such as the Ostomy Adjustment Inventory - 23 (OAI-23) [5], but these mainly measure the patient's social and psychological adjustment to stoma surgery. Instead, it would be important to measure the stoma patient's educational needs to improve motivation to adhere to enterostoma self-care.

The literature shows how greater acceptance and understanding of personal clinical conditions appear to have a positive impact on patient quality of life and reduce setbacks [6, 7]. A case in point is bowel cancer surgery, often resulting in temporary or permanent digestive stoma.

Enterostomal patients need to learn to adjust to and live with altered bodily conditions and intestinal functions. Lifestyle adjustments are therefore needed, and stoma therapy nursing becomes important at this point in the patient's journey towards acceptance [8]. Stoma surgery has a negative impact on quality of life in several ways, such as altered body image, sexual activity, social life, sports and leisure activities [1, 4] and practical, pre-operative stoma training and motivational support [9] are crucial to promote patient recovery and shorter hospital stays [10]. Stoma implies acquiring awareness of and becoming accustomed to changes and restrictions in everyday life [11]. The aim of the study was to develop and validate a "Stoma Acceptance Instrument" that will offer nurses a standard tool to conduct a more uniform and comparable assessment of the needs of enterostomal patients that impact on the acceptance of their new condition, and improve their motivation to participate in their own care. This study is based on Dorothea Orem's Self-Care Theory [12] according to which successful psychological adjustment to self-care and rehabilitation can be achieved through a well-structured, thorough assessment of patient, family or caregiver needs.

Methods

A Stoma Acceptance Questionnaire was developed (Fig. 1). The development of the Stoma Acceptance Questionnaire (SAQ) involved three phases:
1) Conducting ten focus groups to define a set of indicators that improve stoma acceptance, which were used to draw up the items of the questionnaire.
2) Piloting the SAQ questionnaire with 104 patients.
3) Investigation of the aspects of SAQ construct validity.

FOCUS GROUPS

The SAQ was developed through the content analysis of data collected through the focus group methodology. A total of 350 stoma care nurses were involved in a series of 10 focus groups moderated by members of a transnational panel of stoma care experts during the parallel sessions of the Italian national congress of Stoma Care Nurses in October 2010. All the focus groups were audio-recorded for transcription purposes. Each focus group lasted for approximately 1 hour to provide sufficient time for discussions on all topics in the guide.

Due to the large number of participants, data saturation was achieved in two days. The transcripts were independently analysed using NVivo, a qualitative analysis software. Glaser and Strauss's (1967) grounded theory approach, by which empirical data are thematically categorized by induction, was adopted. The themes that emerged from the 10 Focus Groups were discussed by the transnational panel of stoma care experts, who then identified the indicators, which were then used to draw up the items for the SAQ.

Piloting of the SAQ
Tool piloting was conducted in three general hospitals by a group of researchers previously trained on how to use the new assessment tool. Patient inclusion criteria were: no cognitive disorders; a good grasp of spoken Italian; age > 18.

Construct validity of the SAQ
In order to explore the construct validity of the SAQ, we used the Mokken Scale method [10]. Mokken Scaling is a method for detecting unidimensional scales within multivariate datasets; unlike factor analysis, Mokken Scaling – which is a non-parametric form of item response theory – detects sets of items that are related in a hierarchical manner and the software available for analysing Mokken Scales provides a range of parameters whereby the strength of the scale, its reliability and ordering of items can be gauged.

In particular, Mokken Scaling is a non-parametric method that falls under the umbrella of methods described as item response theories (IRT). IRT methods provide a range of parameters that help to identify congruent clusters of items – known as scales. In this sense, they are similar to classical test theory methods such as factor analysis but have the added feature that they seek clusters of items which are hierarchical; the items are ordered in terms of "difficulty" – the extent to which they are endorsed by respondents. For example, if the two items "I feel sad" and "I feel like ending my life" are presented to a group of respondents, we would assume that fewer people would endorse the latter item and this would be the more difficult of the two. Items in Mokken Scales are ordered by their mean score and Mokken Scaling allows us to see how consistently items

Fig. 1. The Stoma Acceptance Questionnaire.

ASSESSING IMPORTANCE
In your opinion, how important is privacy for the family members?
Very much   Fairly   A little   Not at all

How important is it for you to resume your previous sexual activity?
How important is it for you to maintain your level of autonomy?
How important is physical activity for you?
How important is clothing for you?
How important is it for you to not be a burden for the family members?
How important is it for you to have a fixed reference point (i.e. outpatients clinic)?
How important is it for you to resume working?

ASSESSING TRUST
How much do you trust in your ability to manage your stoma autonomously?
How much do you trust in your ability to manage embarrassing situations?
How much do you trust in the support of the family members?
How much do you trust in your ability to follow an adequate diet?
How much do you trust in other people's support?
How much will you be able to accept your stoma?

PROMOTING SELF-DETERMINATION AND RESPONSIBILITY
Do you feel the need to talk with other people who have the same problem?
Now that you are aware of the various types of devices, do you think you will be able to choose/decide which is the most appropriate one for you?
Do you think you are able to manage your life habits now that you have a stoma?

scale – i.e. they are ordered consistently – and this is measured by scalability using Loevinger's coefficient H. The minimum acceptable H is 0.30 for a Mokken Scale to be present.

As reported in the results below, other parameters in Mokken Scaling assist us with decisions about the quality of scales and individual items. Data in an SPSS file were converted to a form suitable for Mokken Scaling analysis using the public domain statistical software R (http://www.r-project.org/) and package "foreign". The automated item selection procedure in the R package "mokken" was used to analyse the data for strength of scale (H), reliability (Rho) and invariant item ordering (HT). The confidence intervals of the items were also examined.

Ethics

Approval was obtained by the ethics committees of all the three public hospitals in Genoa involved in this study. All participants signed an informed consent form. Anonymity, safety and confidentiality of patient data were guaranteed and patient comfort assured.

The study period was from October to December 2010.

Results

FOCUS GROUPS

The themes that emerged from the 10 Focus Groups were: "Living with a stoma"; "Autonomy"; "Support"; "Ability to deal with stoma".

For each theme, the experts identified the following indicators:

1. Living with a stoma: privacy; sexual activity; clothing; embarrassing situations; dealing with daily life.
2. Autonomy: not being a burden for others; resuming same activities before the stoma; trust in oneself; dealing with own stoma/health conditions.

3. Support: support from family members and other people, having a fixed reference point; talking with others who have the same problem.
4. Ability to deal with stoma: know how to choose and use devices; follow an adequate diet; handling sensitive issues.

These indicators were then used to build the 17 items of the SAQ (Fig. 1). A common underlying theme across all these indicators was "Stoma acceptance".

SAQ PILOTING

A total of 104 patients completed the SAQ questionnaire. While completing the questionnaire they were cognitively interviewed by our group of trained researchers to identify if there were any points that needed to be clarified. 75% of all the questionnaires were considered clear and completed.

MOKKEN SCALING

Results of the Mokken scaling are reported in Table I. Two items did not scale and were excluded from the analysis by the automated item selection procedure; two scales were formed, one with 11 items and one with four items; only the first scale, considered here as the one with four items, was not considered useful. A moderately strong Mokken scale (scalability coefficient H > 0.40) with a moderately strong invariant item ordering (HT > 0.40) was derived. Item pair plots were generated and showed minimal intersection between items. A sensible hierarchy of items, ordered by a mean score on items, was obtained ranging from "not wishing to be a burden on the family" (item 6), most strongly endorsed, through items relating to choice and autonomy to the least endorsed items concerning "accepting stoma" and "the importance of physical activity". As the sample size was quite small for Mokken Scaling, based on some very recent work by Kuijpers [11] using marginal models to establish the utility of standard errors and confidence intervals for scalability coefficients, we used the standard errors of the item scalability coefficients (Hi) and the standard errors of the scalability coefficients for item

Tab. I. Mokken scaling of the Stoma Acceptance Questionnaire (n = 104).

Item	Label	Mean	Hi	SE
4	How important is physical activity for you?	2.51	0.48	0.054
14	How much will you be able to accept your stoma?	2.49	0.43	0.058
2	How important is it for you to resume your previous sexual activity?	2.44	0.43	0.062
10	How good do you think you are at handling sensitive/embarrassing situations?	2.43	0.52 0.051	
8	How important is it for you to resume working?	2.25	0.49* 0.055	
9	How good do you think you are at dealing with your stoma / condition autonomously?	2.22	0.55	0.046
17	Do you think you can deal with daily life now that you have a stoma?	2.12	0.50	0.059
12	How good do you think you are at handling sensitive/embarrassing situations?	2.04	0.47	0.055
16	Do you think you will be able to choose the most appropriate device for you?	2.01	0.34	0.079†
3	How important is it for you to maintain your level of autonomy?	1.48	0.47	0.065
6	How important is it for you not to be a burden for the family members?	1.31	0.42	0.079†

H = 0.47; Rho = 0.88; HT=0.41; *-item does not show IIO; SE = standard error; †-confidence interval does not include 0.30

pairs (Hij) to calculate the 95% confidence intervals for each. Since the lower-bound level of scalability is set at 0.3, the confidence interval for items should contain 0.3, whereas for item pairs, the confidence intervals should not contain 0. There was found to be insufficient evidence to support the scalability of items 6 and 16, and that of item pairs 4, 6, and 14 with item 16.

Discussion

Mokken Scaling yielded one interesting and useful scale, again providing new insight into the structure of the SAQ. The item difficulty – the extent to which items were endorsed as shown by their mean scores [10] – ran from items related to not being a burden, autonomy and choice as the most highly endorsed with items related to resuming previous activities and acceptance of the stoma being the least endorsed. This suggests that "not being a burden" and "being able to look after oneself" is most important to people with a stoma, whereas, they are less likely to accept the stoma and find it hard envisaging resuming normal activities. It is conventional to name such hierarchical scales according to the most difficult items and as such, this new scale, which has "acceptance and resumption of normal activities" at the most difficult end of the scale, could be used to measure "acceptance of a stoma". The more respondents endorse items towards the difficult end of the hierarchy, the more they are likely to be accepting the stoma and the scale has potential as a measure of psychosocial and educational interventions to help people accept their stoma. The sample size here was probably at the lower-bound limit for Mokken Scaling [12]; some items had wide confidence intervals and one did not show invariant item ordering (IIO). Unpublished work suggests that these aspects of items in a Mokken Scale are related to sample size, therefore further work with a larger sample size is recommended to test the robustness of the Mokken Scale identified here. Some limits of this study are present as the small sample size and the need to identify additional items to add to the two smaller factors: Autonomy and normality and Trust and burden. This could increase the accuracy of the SAQ. Further another limitation could be the selection of focus group targeted exclusively to nursing workers, and not for example to patients and category associations.

Conclusions

Due to the ageing of the population and the increasing numbers of people with chronic illnesses, the focus of health systems is rapidly shifting from hospitals to primary care prevalently provided in the community [13]. However, in many countries, like Italy, nurses are still not sufficiently prepared and do not have all the tools they need to provide effective primary care in the community [14]. In order to bridge this gap, Italian academic schools need to prepare nurses for advanced practice roles by including clinical modules into their nursing master's degree pro-

grams [15]. However, in addition to being prepared, there is a lack of appropriate tools that would enable nurses to meet the chronic needs of today's ageing population [14]. The SAQ proposed in this study, can be considered a pioneering example of how this gap can be bridged.

The method we adopted to develop an instrument based on the assessment of "stoma acceptance in enterostomal patients" based on meeting the need to resume previous activities yielded new insight into the important connection between 'resuming previous activities' and 'acceptance of the stoma'. Therefore, educational and psychosocial interventions that contribute to the resumption of pre-stoma activities will also be effective in enhancing the level of acceptance of the stoma.

Therefore, the next phase of this research will be to address the limits of this study in terms of increasing the sample size and identifying additional items to add the two smaller factors (Autonomy and normality; and Trust and burden), and subsequently increase the accuracy of the SAQ that will enable to develop more effective educational and psychosocial interventions aimed at improving stoma acceptance, which positively affects adherence to self-care. In this way, it will be easier to measure not only "acceptance of stoma" but also "self-with-a-stoma" [16].

Acknowledgments

Authors' contributions

AB, RW and LS conceived, designed and coordinated the research. AB, MZ and GC collected data. RW and GC performed the data quality control. RW conducted the Mokken Scaling analysis. RW evaluated the results. RW and GA wrote the manuscript. All Authors revised the manuscript and gave their contribution to improve the paper. All authors read and approved the final manuscript.

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■ Correspondence: Annamaria Bagnasco, Assistant Professor of Nursing & Education Coordinator, Department of Health Sciences, University of Genoa, via Pastore 1, 16132 Genoa, Italy - Tel. +39 010 3538515 - E-mail: annamaria.bagnasco@unige.it