

# Lived Experiences of Ostomy Patients Participating in Support groups: A Qualitative Phenomenology Donna Byfield, PhD, RN-BC, CWON

## Introduction

Despite advances in medical treatment for various bowel diseases, between 100,000 and 120,000 ostomy surgeries are performed annually in the United States. Most ostomies are created to be temporary, however, it is estimated that 650,000 to 730, 000 ostomies remain permanently. Currently, there are over one million people in the United States living with ostomies. It is predicated that the number of ostomies will increase by 3% annually with the distribution of procedures being 36.1% colostomy, 32.2% ileostomy and 31.7% urostomy.

Ostomies are constructed as a result of a variety of medical problems including bladder cancer, Crohn's disease, ulcerative colitis, bowel eschemia, diverticulitis, necrotizing enterocolitis, congenital anomalies, trauma and obstruction. Following ostomy construction, individuals find themselves in uncharted territory with a segment of their intestine on their abdomen. Individuals with ostomies may experience lifestyle changes, which include the way they view their bodies, their sexuality, and suffer through physical psychological, and spiritual adaptation.

To prevent complications, the United Ostomy Association, the American Society of Colon and Rectal Surgeons (ARSCRS), the Urological Association (AUA), and the Wound Ostomy Continence Nurse Society (WOCNS) have recommended that all patients scheduled for ostomy surgery have a preoperative visit for stoma siting. With the changes in the health care system and decreased hospital stay, support groups are becoming unique places for caregivers and individuals with different types of medical problems to turn to for education and support. Individuals participating in support groups benefit from the social support and information obtained from the group interaction. While the literature is filled with research on support groups for patients with other health problems, there is limited understanding of the perceptions and experiences of patients with ostomies participating in support groups. Therefore, exploring the lived experiences of ostomy patients participating in support groups may facilitate understanding for health care providers and community service providers on how support groups impact their daily functions.

#### Problem

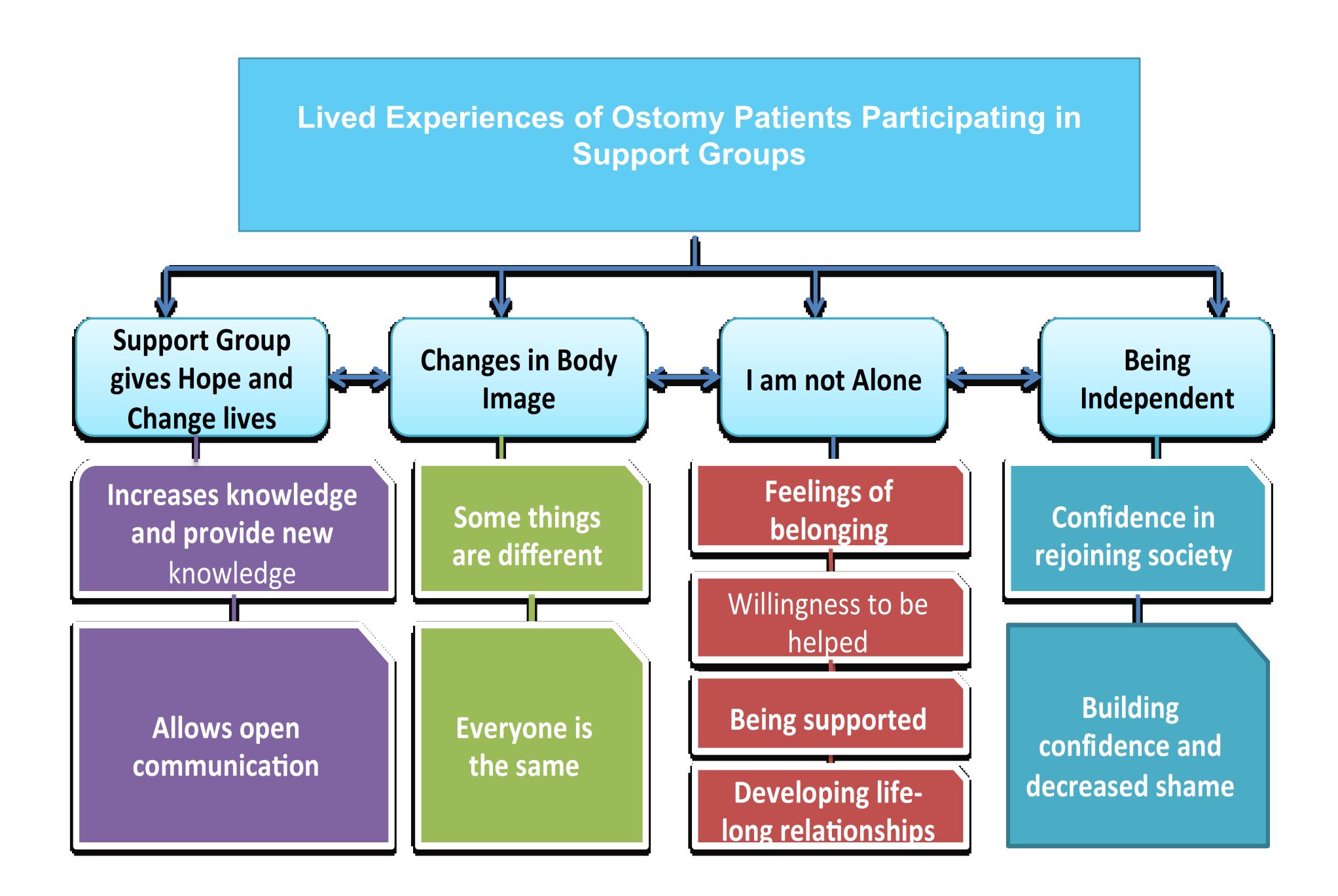
While the literature is filled with research on support groups for patients with other health problems, there is limited understanding of the perceptions and experiences of patients with an ostomy participating in support groups. Therefore, exploring the lived experiences of ostomy patients participating in support groups may provide understanding for health care providers and community service providers who are interested in learning about patients with ostomies, and how support groups affect their daily functions.

#### Methods

A descriptive qualitative phenomenological design was used following Review Board approval.

- Sample size: purposive sampling to recruit participants (n=53); Response to invitation (n =15); Total sample (N=10) due to data saturation. Participants ages ranged from 51-90 years; 5 F and 10 M.
- Inclusion criteria: participants with any type of ostomy, attending a support group in Georgia, speaks, reads and understanding English. Ages between 18-89 years and able to sign an informed consent form.
- Exclusion: anyone who did not meet the inclusion criteria.
- Tools: qualitative data collected using semi-structured open-ended questions lasting 45 to 60 minutes. The data was digitally voice recorded and then imported into Nvivo 11 software twice to further clarify coding and identifying themes and sub-themes. Data analyzed inductively using thematic analysis according to Parse analysis method.

#### Results



# Conclusion

Construction of an ostomy can be devastating to individuals and can affect outcome and quality of life (QOL). Ostomy construction is one of the leading treatments for rectal cancer and other medical conditions. The number of ostomies being constructed for different medical conditions are increasing. Knowing how ostomy patients define the benefits, what impact support groups have, not only on QOL but also on the adverse consequences and complications from ostomies..... Unfinished sentence

The finding revealed that participating in support groups allow individuals with ostomies to function at higher levels than they were functioning before participating in the support group. The outcome characterized by lived experiences include hope, willingness to live fully again, participating in different activities and making new friends.

### References

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