

OUR LIVES

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AIMS

This was a small research study that we conducted to explore the lives of individuals with a stoma.

As experienced stoma care nurses we think we know what a typical day for people living with a stoma looks like, but do we really? Do we really understand the depths of how living with a stoma can and does affect some individuals' lives so profoundly?

As nurses working in the specialist sphere of stoma care we strive to acquire further insights into our patients' needs and wants when living with a stoma, how they adapt to new challenges and different environments. We were also keen to develop a deeper understanding on how having a stoma can impact an individuals' physical, psychological, and social wellbeing.

METHOD

A phenomenological style of research was adopted, as phenomenology is concerned with the lived experience of humans, which focuses on a deeper and fuller meaning of the individual, with its disciplinary roots in both philosophy and psychology.

As phenomenological researchers we were keen to understand how individuals living with a stoma perceive their own quality of life and describe their everyday lives.

Day in life studies are a simple way of trying to see the world through that individuals eyes, capturing what they do, why they display certain behaviours and what happens around them.

The goal was to gain qualitative data of the lived experience of individuals to uncover and possible trends in their thoughts and opinions, and investigate further into their lives.

We used semi-structured interviews to gather focused data. This form of data collection allowed the discovery of rich descriptive information on the personal experiences of individuals and the use of pre-determined questions provide uniformity with each individual. Open-ended questions were used as they enable the respondents to impart more information, including feelings, attitudes and coping mechanisms.

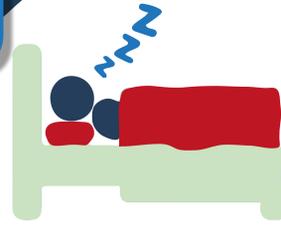
LITERATURE REVIEW

A literature review was conducted to explore what evidence is already known about the lived experience of individuals with a stoma.

Not surprisingly, much of the literature suggests that having a stoma can influence many aspects of daily life. As stoma nurse specialists we are fully aware of the physical challenges some patients can face when learning to cope with their stoma care, especially whilst practicing and trying to become confident in its management. In addition we also acknowledge the impact that living with a stoma can have on individuals' psychological and emotional wellbeing. This can be short term or have long-lasting consequences that affect aspects such as body image, sexuality, relationships and emotions.

SLEEP

In some way sleep was reported by all the participants as "disrupted" on a daily basis. Some individuals believed it to be due to pouch emptying or pouch changes, others as a result of ballooning, leakage or simply fear that the pouch would leak. There was an overall feeling that individuals living with a stoma often struggled to get a good night sleep.



STAYING AWAY FROM HOME

Staying away from home seemed to cause anxiety due to fear of leaks, unfamiliar surrounds and being away from home comforts. As well as concerns regarding where used pouches could be safely disposed of, without causing embarrassment.



STOMA MANAGEMENT

Some of the individuals reported that they had no difficulty or issues with stoma care management and perceived themselves as confident with stoma care. Whilst some outwardly suggested they had no issues when discussing and /or demonstrating their actual routine, it became apparent that most were extremely fastidious in management and did not sway from their fixed routine. Any deviation to that routine had the potential to cause anxiety.



CLOTHING

Clothing was depicted by some individuals as a concern that impacted on their daily routine. Some considered it was necessary to alter their clothing to accommodate the pouch. Others also felt the need to change their style of fashion or resorted to wearing more comfortable clothing over their pouch. Much of this caused feelings of frustration and irritation due to the enforced change or limited choice of clothing.



HOW LIVING WITH STOMA CAN IMPACT ON EVERYDAY LIFE

Focusing on different aspects of their daily routines to gain a deeper insights into the participants daily life were broken down into these areas



EMPTYING THE POUCH

The issue of emptying the pouch, was a particular concern expressed by individuals living with a urostomy or ileostomy. The problems the reported included the need to frequently empty the pouch, insufficient cleaning facilities/space in public bathrooms, as well as the availability of appropriate bathrooms.



JOURNEYS

Travelling by any means of transport appeared to cause a certain degree of anxiety for most individuals, especially in relation to stoma management. Whether travelling on a plane, train or by car, practical stoma management such as emptying or changing a pouch resulted in some form of apprehension and uncertainty.



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CONCLUSION

By facilitating day in the life interviews with individuals living with a stoma, it has enabled us to ascertain a rich body of data that can subsequently provide us with an empathetic insight and deeper understanding of what a typical day for people living with a stoma may look like and how that can affect their everyday life. This knowledge can then influence clinical practice and pathways of care, which will result in an improved quality of care for individuals living with a stoma.