

A STUDY OF THE QUALITATIVE IMPACT OF NON-MEDICAL SWITCHING OF OSTOMY SUPPLIES

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Introduction

"I have had an ileostomy for over 30 years. For decades I've had a properly fitted pouching system. Recently, my supplier changed my preferred choice of products for non-medical reasons and I am now restricted to using a different brand, which does not have the same quality of product in durability and reliability to meet my stoma needs. I have issues with the attachability and the seal can fail with the location of my stoma and physique. I am now experiencing leakage also in the back of the adhesive and that never happened before. Now I have to order more products and pack more supplies to have with me at all times, because when you have a less reliable ostomy product, you need to change more frequently and compensate by adjusting how you live your life and what you do."

"I use Brand X products: two-piece wafers and pouches, and deodorant lubricant. I requested the Brand X protective barrier wipes, barrier remover wipes and skin cleaning wipes; all items manufactured by the same company. I want the consistency of using the same products by one company. My insurance refused to cover the protective barrier wipes, barrier remover wipes and skin cleaning wipes with no reason given or explained. The ostomates know what works best for them. These items are not a luxury, but a NECESSITY!!!! Insurance should not stand in the way of our care. Cheapest is not always the best."

A Very Real Life Story

These are real-life stories of a practice called “non-medical switching” (NMS). This is becoming a common plight for patients who use ostomy prosthetic supplies. Many patients are familiar with this cost-shifting tactic and terminology as it relates to medication and insurance companies forcing patients to change their medication to a lesser expensive drug. Non-medical switching also occurs for patients who need medical supplies such as ostomy supplies, urologic supplies such as catheters, tube feeding supplies and inhaler products to name a few.

For stable ostomates non-medical switching occurs when health insurers or suppliers change their current reliable pouching system to different products for non-medical reasons typically on the basis of cost. This may result in increased doctor visits, emergency room visits and possible rehospitalization. Non-medical switching critically affects a small percentage of the ostomy patient population.

The unexpected outcome of non-medical switching for the person living with an ostomy is that health and wellbeing may be jeopardized. When they are unable to obtain their prescribed ostomy supplies, defined as a prosthetic device, the ability to effectively manage their ostomy may be hindered. This can affect all aspects of the ostomate’s quality of life not only physically, but emotionally due to the stressors of change and/or the switched product not working as well.

There are a number of different approaches to switching for non-medical reasons that an ostomate may encounter, including:



Insurers stop covering the particular medical device (in this case components of the ostomy pouching application system) or remove it from their formulary, forcing patients to pay out-of-pocket for the device that is already working well for them.



Some suppliers “switch out” what was prescribed and substitute generic, poorer quality, or less expensive brands without consulting the patient or the prescribing medical professional.



Insurers may restrict consumers to specific brands or specific suppliers, which limits patient access to the products they need. Patients often must use products from multiple manufacturers.



Health care facilities such as hospitals (including LTAC, and rehabilitation hospitals), skilled nursing facilities and home health agencies switch what a person uses for their in-house formulary brand.

Impact Brief

The ostomy community has long been recognized as an underserved community. A study of the impact of non-medical switching for users of ostomy supplies has never been conducted. To fill this gap, this report presents findings from a 2024 national online survey of 150 patients who experienced non-medical switching out of more than 300 respondents. These data points and their personal experiences give us a closer look, including the following:



Value of the Right Supplies

Every ostomy product is good for someone, but not every product is good for every person with an ostomy. Patients who have worked with a medical professional and found a combination of products that result in a comfortable, predictable and consistent wear time, adapt positively to an ostomy and are able to live a life they enjoy. Respondents unanimously (**100%**) placed a high value on having access to the right supplies. The importance of patients and healthcare providers being involved in any medical decisions that will impact their health was indicated by **98%** respondents.

Impact on Quality of Life (QOL)

Quality of life is a sense of well-being physically, emotionally and mentally, and can be achieved for the person living with an ostomy with correct and well-fitting products. This brings the security needed to function well at home, socially and in the community as a whole. Over **50%** of respondents experienced a disruption in quality of life from non-medical switching.



Negative Medical Consequences

Maintaining skin and stoma health is of utmost importance to those living with an ostomy. A majority (**64%**) of patients responded that their ostomy care was negatively impacted physically from NMS which included a medical complication or the need to visit an MD or the emergency room.



Impact on Mental Health Well-Being

Patients also experience non-medical switching on an emotional level. **83%** of patients who were not informed that their products would be switched or who were suddenly expected to learn how to use new products, or the products did not meet their needs, felt their mental health was negatively impacted including greater anxiety and feelings of frustration and anger.



Economic Burden

Most patients living with an ostomy rely on insurance coverage to ease the financial burden of these necessary supplies. For many patients who experienced NMS (**56%**), there were increases in health care costs and out-of-pocket expenses.



Background

People of all ages have life-saving ostomy surgery, including infants. Patients who have undergone ostomy surgery rely on a pouching system for the collection of bodily waste for the period of time that they have the ostomy which could be from a few months or for life.

Ostomy supplies are defined as prosthetic devices under the Social Security Act since they replace and restore the lost functions of waste storage and elimination.¹ There are multiple options for pouching systems to meet the unique needs of the ostomate. Criteria for evaluation include stoma type, size and characteristics, output, abdominal contour, placement of the stoma and peristomal skin health.

Many ostomy products are similar, but they are not the same. Each manufacturer has a different chemical composition of their product adhesives and pouch fabric material. Other differences include size ranges, style of closure, style of coupling system (2-piece systems), style of one-piece systems, style of filtering system and ability to wear an ostomy belt.

Ostomy accessory products also differ (e.g. skin barrier wipes/sprays, adhesive remover wipes/sprays, seals, paste, deodorants) and can be just as important as the pouch itself. A successful “pouching prosthetic system” is a combination of pouch type and accessories to achieve proper fit that is well-sealed.

It is an ostomy patient's right, and recognized as a standard of care, to have access to specific and individualized ostomy supplies chosen in consultation with a health care provider to achieve and maintain a reliable fitting pouching system.²

Evidence has shown that access to compatible and securely fitting ostomy products is imperative to improve patient outcomes and avoid medical consequences such as peristomal skin complications (PSCs) and hospital readmissions.³⁻⁴ Best practice guidelines for ostomy care include the correct use of well-fitting ostomy products that provides a reliable and predictable wear time without leakage.⁵⁻⁶ Additionally, access to and utilization of a variety of products such as rings, seals and stoma skin powder is necessary for intervention and treatment of PSCs.⁷

Change to an individual's prescribed pouching system for non-medical reasons can lead to medical consequences such as trauma to the stoma and peristomal skin complications (PSCs). PSCs due to repetitive leakage onto the skin increase use of ostomy supplies from frequent appliance changes. Medical consequences include increased outpatient clinic needs, emergency visits, financial hardship for the patient⁸ and an increase in burden of cost across the healthcare system.⁹ Quality of life for the patient can also be negatively affected.

“Supplies are personal and individualized. Imagine if the insurance company told you what type of underpants/boxers/briefs you had to wear.”



Finding the Right Ostomy Supplies

Responses clearly conveyed:

100%

Place a high value on having the right supplies

98%

Believe that they and their health care provider should be a part of any medical decision that will impact their health

74%

Reported it hard to initially find the products that worked for their medical needs (e.g. proper pouch fit/seal)



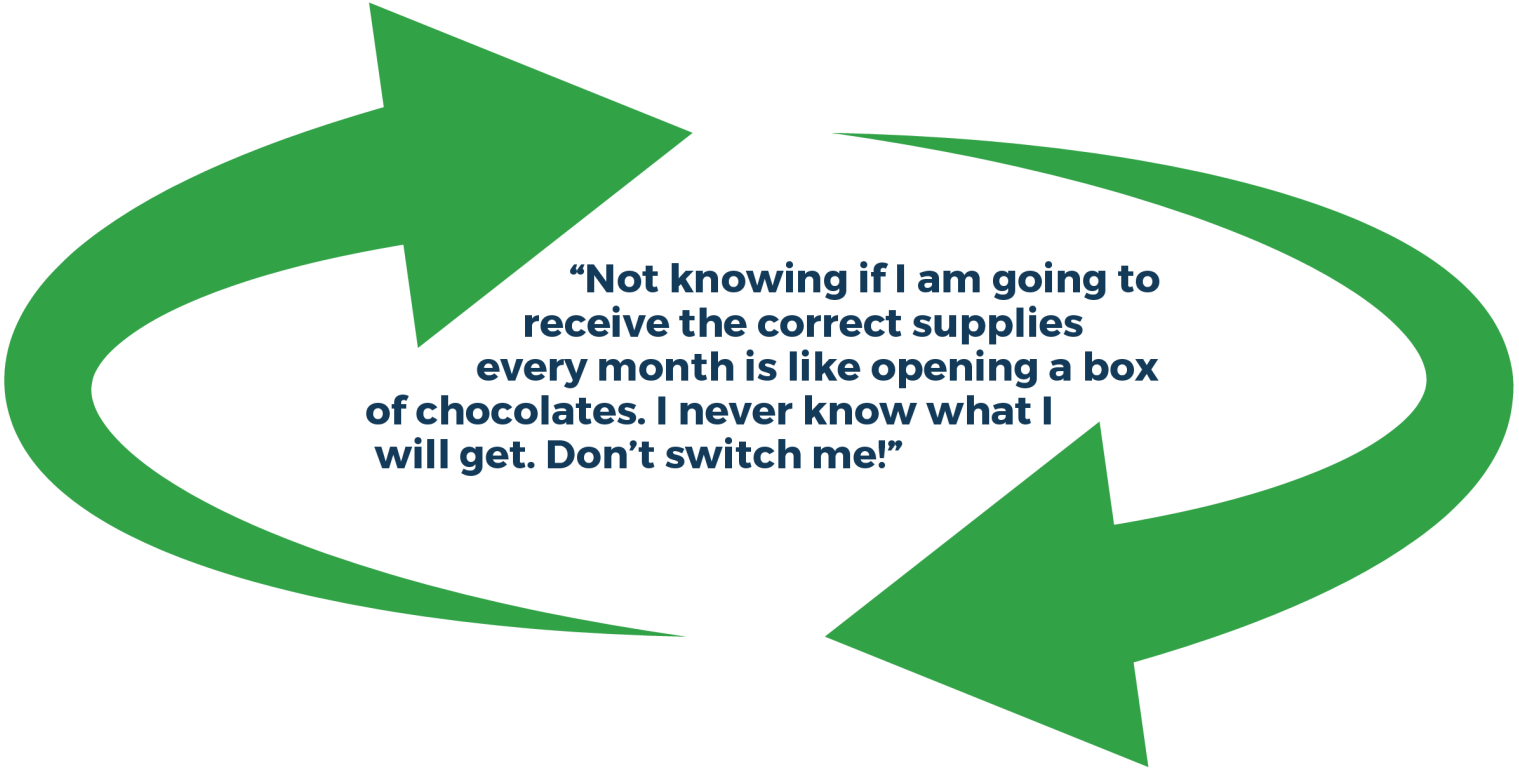
Non-medical switching does not acknowledge each person's individual ostomy needs and does not support clinical decision-making. It removes the collaborative process between the medical professional and ¹⁰ patient substituting a cost-cutting strategy by non-medical staff. Better outcomes occur, and patients are more satisfied when medical providers and patients, not non-medical third parties, make decisions regarding ostomy products best suited for each individual.

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“It took a long time to find an appliance that works for me and doesn't leak daily. I live in fear that my insurance or supplier would discontinue my access.”

Surprise: The Switch!



“Not knowing if I am going to receive the correct supplies every month is like opening a box of chocolates. I never know what I will get. Don’t switch me!”

Third-party payers may make their own financial interests a priority over the medical needs of a patient. They may be unwilling to cover the products that have been carefully chosen for the unique needs of the ostomy patient or they may choose to cover different and less expensive products as a cost-saving strategy. Patients often have been limited to formularies in health care facilities that do not include the products used by the patient. In addition, some distributors have also been found to steer patients towards products that differ from the products prescribed or may make the decision to substitute products altogether.

It is important to recognize that some insurers are driving independent durable medical equipment (DME) or home medical equipment (HME) providers out of business by not paying them enough to cover their costs. Small suppliers have little choice but to accept these low reimbursement rates, “substitute” products or close their doors. When reimbursement rates are not sustainable it puts constraints on the distributors and results in supplies oftentimes being switched or substituted for economic reasons.¹⁰ This limits health care access, hurts consumers and accentuates the problem of non-medical switching.

Additionally, “non-consented switching” means that patients do not receive any instruction from their medical provider about how to use the new product. Patients are trained after surgery and prior to discharge on the care and management of their ostomy, ideally by a nurse certified in ostomy care. When a patient experiences non-medical switching for their ostomy supplies, this may result in a lack of understanding of how to use the 'new' product and may result in a poor fit and seal.

Findings Showed

96%

Were upset that they weren't involved in a decision that seriously impacted their health, wellbeing and life

86%

Were NOT notified in advance by their health plan or supplier that a switch would be happening

58%

Were never able to get a resolution following the switch



Patients reported the following ways of being switched:

12%

Insurer restricted me to a specific brand

14%

Insurer restricted me to a specific supplier

22%

Insurer eliminated coverage for certain products

63%

Supplier substituted my products with something different

22%

Supplier restricted me to a specific brand

22%

Other (please specify) (Most written responses were "my supplier quit carrying a specific supply item" or "manufacturer discontinued a product")



Negative Medical Consequences

“Nobody except for my physician and I should make decisions regarding any of my health care. When others make decisions that are not my physician or I, they do not know all aspects of what is needed for my health care so I end up having extra problems, wounds and infections.”

Non-medical switching is a chronic problem that harms patient access to their medically necessary supplies and in the worst cases patients can suffer serious health consequences.

64%

Reported that their ostomy care has been negatively impacted by non-medical switching

32%

Respondents had to make appointments with specialists such as a certified Wound Ostomy Continence nurse

25%

Respondents experienced a medical complication from the new products they were switched to

21%

Respondents needed to visit their healthcare provider more frequently after the switch

13%

Visited an emergency room, hospital or medical doctor as a result of having their products switched



If It Ain't Broke, Don't Fix It

“Having an ostomy is hard enough without feeling like our unique medical supply needs are not considered. It feels disrespectful when you order a product just to see that they gave you an inferior product with no warning or reason.”

“Any supplies should never be changed, no matter how irrelevant it may seem to anyone. The patient should not have to sacrifice at any time.”

Patients in this survey were utilizing products that were already working for them and enabling them to achieve quality of life with an ostomy. Those who experienced NMS felt that they were pushed into a new product and were not satisfied with the switched product. It negatively affected them physically, emotionally, mentally and in some cases financially. Many experienced consequences that disrupted their ostomy care, their ostomy health and/or ability to get the products that they had come to depend on.

- **78%** have NOT been satisfied with the switched products
- Non-medical switching has resulted in **25%** of patients having to change their pouching prosthetic system
- For people whose switched product did not work for them, **29%** were never able to find a new product to work for them. **33%** of respondents took one month or longer to find a product that worked for them and for **10%** it took 6 months or longer.
- **60%** did NOT have any assistance in finding a new product(s) that would be covered.

Effects of Non-Medical Switching are More Than Skin Deep

The trickle-down effect of being forced to switch supplies for non-medical reasons can upset patients' day-to-day lives in many different aspects. A **majority** of respondents reported the switch disrupted their overall quality of life.

62%

Reported that it did not impact other areas of their lives, but for others there were some areas of home and work life impacted (respondents could check all that applied):

38%

Reported that their work or life schedule was interrupted by added healthcare needs

28%

Negative impact on social life such as going out with friends, eating at restaurants

21%

Unable to continue regular hobbies or activities

18%

Became homebound and experienced isolation

18%

Unable to attend or fully participate in life events such as birthdays, holidays, or vacations

11%

Missed work due to problems or medical appointments related to new products

11%

Relationship with a family member or friend suffered

7%

Unable to be productive at work

6%

Unable to care for my children, grandchildren, spouse, parents or other family members like I needed to



‘It’s Renting Space in my Head’

Non-medical switching is not a good tenant to have there. Non-medical switching is another ongoing stress that patients have to deal with along with the stressors that are already a part of life. It can be traumatic for a patient who has used the same brand supplies for over 30 years to be switched to something different.

Ostomates rely on their pouching system not failing so they can lead full independent lives without constant worry, fear or embarrassment of a leak. If patients don’t have access to the supplies that they have come to rely on, some for many years, the impact on a holistic level can feel insurmountable and affects their mental health and emotional well-being.

“Most frustrating experience of my life. I never, ever, would have thought that the supplies I needed would be in jeopardy. Just to get anyone to listen was, at first, impossible.”

Respondents admitted that the switch left them feeling:

83%

Frustrated

50%

Anxious

28%

Helpless

24%

Confused

19%

Fearful

18%

Other (please specify)

(15 out of 22 open-ended responses were “angry” and/or “pissed off”)



Cost an Arm and a Leg

(Or in the case of ostomy supplies, make that “a colon and a bladder”!)

“I’m tired of hearing explanations like, talk to Medicare, they set the criteria, your insurance sets the guidelines, talk to them. How much more penny pinching will occur until the penny pinchers can’t pinch any more pennies and costs are passed on to the consumer at an ever slow rate?”

Non-medical switching is a profitable practice. It shifts costs of care to the patient when they can’t utilize ineffective substituted supplies. Any savings realized by the insurer or supplier comes at the expense of the patient. If a patient refuses the “switched” product, they must shoulder the cost of the treatment on their own, increasing their financial burden of care. The patients are then forced to appeal a non-medical decision when they have collaborated with their physician and determined which products function successfully for them. If they can not afford to purchase the effective products, they are forced to utilize ineffective products. Patients are more than the bottom line. Respondents reported:

56%

Non-medical switching resulted in increased health care costs

59%

Had to order and purchase more supplies until they found a comparable product that would be covered by their insurer

46%

Declined the products that were switched and paid-out-pocket for what they needed

The Rest of the Story

Data points by themselves don’t paint the full picture. Patient testimonials speak volumes about why non-medical switching is a problem.

“Suppliers should not choose MY SUPPLIES from a catalog when my nurse worked with me for weeks to find supplies that worked for ME!”

“It took me a while to find the right product in the beginning and to suddenly have the product switched was a real problem with skin irritation and quality of the devices. This all occurred when I went from commercial insurance to Medicare!”

“I don't think a supplier or distributor should ever be allowed to change patients' ostomy supplies without a doctor's reason and prescription to do so. I, along with many others, have skin sensitivities and even anaphylactic reactions to some chemicals in the pouch adhesives. This could be a life threatening change for some and a huge liability to the distributor for wanting to save money. We aren't cars and can't always use aftermarket parts.”

The Rest of the Story (continued)



"I've had an ileostomy for 30+ years. It is terrible when manufacturers discontinue products and suppliers switch supplies without consulting or informing clients. I've had dozens of products discontinued, dozens that weren't discontinued but my supplier wouldn't get them for me. It is only getting worse as the number of people with ostomies is reduced. One size doesn't fit all!"



(Author's note: The survey also showed that some patients were not affected by non-medical switching and some were affected in a positive way because it gave them an opportunity to use a product they had never tried or knew about. Some patients are never exposed to alternative products from what they were prescribed in the hospital following their ostomy surgery. Below are some patient comments:



"I ended up liking my new brand of ostomy supplies. I was anxious that I wouldn't as I had been using the same brand for over 10 years but I must say, I like my new brand even better. It was scary to switch brands but finding a reliable supplier was even scarier to me. I have had issues with previous suppliers and really liked the one I was currently using so I'm very glad that I tried the new brand and like it."



"As a new ostomate I was not aware that the blistering under my pouch caused by the adhesive could be better controlled. Being sent a cheaper barrier ended up working better for me as it works against the adhesive and I no longer have blisters. Without the switch I may have gone months before we changed barrier brands. So it worked great for me but I'm sure there are more patients negatively affected by the changes."



Access to Proper Ostomy Supplies Matter

"Please help us."

Ostomy supplies are prosthetic supplies that replace the function of lost organs (e.g., bladder, colon). If someone has a prosthetic arm that has been working for them all along and then somebody (other than their medical team) decides they should use this other one (that doesn't fit properly) because it is what they chose for them, this would never be an acceptable practice. Ostomy products should not be treated any differently than other prosthetics.

The practice of non-medical switching, whether it affects one patient or thousands, is wrong and can result in negative consequences. The findings of this survey must be taken as a warning that something harmful is happening to these patients and we need to advocate that it stops.



"It should be written into law that prevents this type of situation from happening."



"The physical and psychological impact of non-medical switching cannot be quantified in dollars and cents or in the passing of time. Its effects are immediate and dangerous but also lasting and damaging. There is a relationship with my stoma and how I felt about the lifesaving surgery I underwent and the experience made me regret a choice I previously celebrated. This impacted me, my family, my friends, my relationship with my doctors and nurses, and my interactions with my insurance company. The importance of ending this cannot be overstated."

References

1. Title XVIII, §1861 (s)(8) of the Social Security Act defines prosthetics as those, which replace all or part of an internal body organ, including colostomy bags and supplies directly related to colostomy care, and replacement of such devices.
2. "Ostomy and Continent Diversion Patient Bill of Rights." Ostomy.Org, United Ostomy Associations of America, Inc., 2021, www.ostomy.org/wp-content/uploads/2021/08/UOAA_Patient_Bill_of_Rights_Poster_20210806.pdf.
3. Taneja C, Netsch D, Rolstad BS, Inglese G, Lamerato L, Oster G. Clinical and Economic Burden of Peristomal Skin Complications in Patients With Recent Ostomies: J Wound Ostomy Continence Nurs. 2017;44(4):350-357. doi:10.1097/WON.0000000000000339
4. Taneja C, Netsch D, Rolstad BS, Inglese G, Eaves D, Oster G. Risk and Economic Burden of Peristomal Skin Complications Following Ostomy Surgery. J Wound Ostomy Continence Nurs. 2019;46(2):143-149. doi:10.1097/WON.0000000000000509
5. Wound Ostomy Continence Nurses Society. Clinical Guideline: Management of the Adult Patient with a Fecal or Urinary Ostomy. Wound Ostomy Continence Nurses Society; 2017.
6. Ostomy Guidelines Task Force; Goldberg M, Aukett LK, et al. Management of the patient with a fecal ostomy: best practice guideline for clinicians. J Wound Ostomy Continence Nurs. 2010;37(6):596-598.
7. Salvadalena G, Colwell JC, Skountrianos G, Pittman J. Lessons Learned About Peristomal Skin Complications: Secondary Analysis of the ADVOCATE Trial. J Wound Ostomy Continence Nurs. 2020;47(4):357-363. doi:10.1097/WON.0000000000000666
8. Hedric, Traci L., et al. "AGA Clinical Practice Update on Management of Ostomies." Clinical Gastroenterology and Hepatology Journal, American Gastroenterological Association, 25 July 2023, [www.cghjournal.org/article/S1542-3565\(23\)00495-0/fulltext](http://www.cghjournal.org/article/S1542-3565(23)00495-0/fulltext).
9. Colwell JC, Pittman J, Raizman R, Salvadalena G. A Randomized Controlled Trial Determining Variances in Ostomy Skin Conditions and the Economic Impact (ADVOCATE Trial). J Wound Ostomy Continence Nurs. 2018 Jan/Feb;45(1):37-42. doi: 10.1097/WON.0000000000000389. PMID: 29300287; PMCID: PMC5757663.
10. "The Critical Need to Provide Ostomy Supplies Specific to Patient Need to Improve Health Outcomes." AAHomecare www.aahomecare.org, 15 Apr. 2024.

