








# Factors associated with self-care practiced by people with intestinal elimination stomas

*Fatores associados ao autocuidado praticado por pessoas com estomias de eliminação*

*Factores asociados al autocuidado practicado por personas con estomas de eliminación*

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## ABSTRACT

**Objective:** to evaluate the factors associated with self-care practiced by people with elimination stomas. **Method:** analytical cross-sectional study, based on the responses of 153 people with elimination stoma, treated at a reference outpatient clinic for the care of people with stoma, in the city of Teresina. Data collection took place through a semi-structured form with demographic data and about self-care. Analyses were performed using inferential statistics, using the chi-square test. **Results:** Emptying the pouch, cleaning the stoma, drying the peristomal skin, detaching the plaque, measuring the stoma, making the mold, fitting, self-esteem and social isolation were significantly associated with self-care ( $p < 0.05$ ). **Conclusion:** it was evident that the factors associated with self-care were care for the stoma and the collection equipment, in addition to the impacts on self-esteem and social life.

**Descriptors:** Enterostomal Therapy; Surgical Stomas; Self Care.

## RESUMO

avaliar os fatores associados ao autocuidado praticado por pessoas com estomias de eliminação. **Método:** estudo transversal analítico, baseado nas respostas de 153 pessoas com estomia de eliminação, atendidas em um ambulatório de referência no cuidado de pessoas com estomas, no município de Teresina. A coleta de dados ocorreu por meio de um formulário semiestruturado com dados demográficos e acerca do autocuidado. Os dados foram analisados mediante estatística descritiva e inferencial. O teste Qui-quadrado de Pearson foi utilizado na análise inferencial. **Resultados:** o esvaziamento da bolsa, limpeza do estoma, secagem da pele periestoma, descolamento da placa, medição do estoma, realização do molde, adaptação, esvaziamento da bolsa, autoestima e isolamento social apresentaram associação significativa com o autocuidado ( $p < 0,05$ ). **Conclusão:** evidenciou-se que os fatores associados ao autocuidado foram os cuidados com o estoma e com o equipamento coletor, além dos impactos na autoestima e na vida social.

**Descritores:** Estomaterapia; Estomas Cirúrgicos; Autocuidado.

## RESUMEN

**Objetivo:** evaluar los factores asociados al autocuidado practicado por personas con estomas de eliminación. **Método:** estudio transversal analítico, basado en las respuestas de 153 personas con estoma de eliminación, atendidos en un ambulatorio de referencia para la atención de personas con estoma, en la ciudad de Teresina. Se realizó la recolección de datos a través de un formulario semiestructurado con datos demográficos y sobre autocuidado. Los datos se analizaron utilizando estadística descriptiva e inferencial, utilizando la prueba Chi-cuadrado de Pearson. **Resultados:** vaciar la bolsa, limpiar la estoma, secar la piel periestomal, despegar la placa, medir la estoma, hacer el molde, adaptarlo, vaciar la bolsa, la autoestima y el aislamiento social se asociaron significativamente con el autocuidado ( $p < 0,05$ ). **Conclusión:** se evidenció que los factores asociados al autocuidado fueron el cuidado de la estoma y del equipo de recolección, además de los impactos en la autoestima y la vida social.

**Descriptor:** Estomaterapia; Estomas Quirúrgicos; Autocuidado.

## INTRODUCTION

Ostomy is a term derived from the Greek *stomoum*, which means “opening of some empty viscera through the body”. Performance of an ostomy is considered an invasive procedure for the patient, and can be classified as temporary or permanent, according to the particularity of each disease<sup>1-3</sup>. The most common types of ostomies are colostomy and ileostomy for stool diversion and urostomy for urine diversion<sup>4</sup>.

After undergoing the surgical procedure, people with ostomies begin to face physical, psychological and social barriers that hinder their rehabilitation<sup>5</sup>. Thus, it is important to emphasize that, in addition to the need to use collecting devices, there are also changes in daily activities, such as body hygiene, clothing and feeding, which can cause low self-esteem. In addition to that, people with ostomies may encounter difficulties in the social environment due to lack of adapted toilets<sup>2</sup>.

While some stomas can be temporary, there are circumstances that require them to remain for months or permanently. In these situations, guidelines on self-care are necessary to reduce complications<sup>5</sup>.

A study carried out to evaluate the effectiveness of self-care in patients with ostomies found that the patients who received more information during hospitalization had greater autonomy in management of their ostomies and better self-care maintenance<sup>6</sup>.

For Dorothea Orem, self-care practicing activities that an individual initiates and performs for their own benefit, in maintenance of their life<sup>8</sup>. When there is an imbalance between the existing demands and the possibility of carrying out these actions, there is a self-care deficit<sup>7</sup>.

The deficits experienced by people with ostomies, especially related to the execution of procedures for cleaning the stoma and for emptying and exchanging bags, can be evaluated according to the Self-Care Deficit Theory, which signals the competence of this person to take care of themselves and others who may be under their responsibility<sup>9,10</sup>.

Ordinance number 400 of 2009, of the Ministry of Health, established the national guidelines for the creation of health care services for people with ostomies in the Unified Health System. The decree determined that people with ostomies have the right to assistance in basic health units, outpatient clinics and specialized places, with the objective of improving assistance and considering two levels of services. The first service is Care for People with Ostomies I, which provides specialized assistance of an interdisciplinary nature to people with stomas, aiming at their rehabilitation and with the objective of guiding self-care and preventing complications in ostomies, as the legislation guarantees the free distribution of collecting devices and protective and safety adjuvants. Service II follows the same pattern as Service I, adding a larger multidisciplinary team, treatment of complications arising from the ostomies and training of professionals<sup>11</sup>.

In view of the changes in social and personal life related to the presence of temporary or definitive ostomies, this study aimed at evaluating the factors associated with self-care practiced by people with elimination ostomies.

## METHOD

This is an analytical and cross-sectional study conducted in a Type II outpatient clinic of municipal reference, which provides assistance to people with ostomies throughout the state of Piauí, with data collection from February to March 2023 and non-probability sampling, obtained by convenience.

The study included people with elimination ostomies, aged at least 18 years old and in regular follow-up at the aforementioned outpatient clinic. Patients with syndromes, dementias and/or other conditions that limited cognition and prevented answering the questionnaires were excluded, as well as those aged at least 60 years old who did not reach the minimum score (seven) in the mental assessment questionnaire<sup>12</sup>, used to investigate cognitive impairment and dementia in older adults.

For data collection, a semi-structured form was used, developed by the outpatient clinic and adapted by the researchers to include demographic data about self-care, organized and divided into four parts: personal data, clinical characteristics, self-care, and guidelines. To identify self-care autonomy, the participants answered in the form whether they performed the self-care practice alone, with help or if it was in charge of the caregiver.

Upon agreeing to participate in the study, the people with ostomies were directed to a reserved outpatient room.

The dependent variable was self-care and the independent variables were sociodemographic, clinical, self-care practices, adaptation, pre- and post-operative guidance and social and sexual image.

The study data were entered into *Microsoft Office Excel*® databases and subsequently processed in the *Statistical Package for the Social Sciences* (IBM SPSS®) software. A descriptive analysis of the data related to the sociodemographic and clinical variables (absolute frequencies, percentages, mean values and standard deviations) was performed. In the inferential analysis, Pearson's Chi-square statistical test was applied. Values referring to  $p < 0.05$  were considered significant.

It is noted that all ethical precepts foreseen in Brazil for research with human beings were respected. In this perspective, this study was approved by the Research Ethics Committee of the institution involved, in accordance with Resolution No. 466 of 2012 and other supplements of the National Health Council.

## RESULTS

The study included 153 individuals with elimination ostomies. Data collection lasted a mean of 20 minutes, respecting the individuality and ethical principles of the research.

Regarding the participants' profile, it was possible to observe that among the 153 individuals with ostomies, 82 were male (53.6%), with a mean age of 56 years old ( $\pm 17.0$ ), 71 were married (46.4%), 67 had Elementary School (43.8%), 68 were retired (44.4%) and 77 earned monthly incomes of up to two minimum wages (50.3%). In addition to that, 105 identified themselves as financially responsible for their family (68.6%).

The data related to clinical variables are presented in Table 1.

**Table 1:** Description of the clinical variables of people with elimination ostomies treated at a reference outpatient clinic in Piauí (n=153). Teresina, PI, Brazil, 2023.

	Variables	n	f(%)
<b>Baseline disease for the stoma</b>	Colorectal cancer	69	45.1
	Intestinal trauma injuries	13	8.5
	Firearm perforation	11	7.2
	Bladder cancer	10	6.5
	Uterine cancer	8	5.2
	Diverticulitis	8	5.2
	Problems arising from intestinal obstruction	7	4.6
	Crohn's disease	4	2.6
	Appendicitis	3	2.0
	Other	20	13.1
<b>Mobility</b>	Walks	139	90.9
	Walks with help	8	5.2
	Does not walk	6	3.9
<b>Stoma permanence time</b>	Temporary	79	51.6
	Definitive	66	43.1
	Undetermined	8	5.3
<b>Type of stoma</b>	Colostomy	105	68.6
	Ileostomy	33	21.6
	Urostomy	15	9.8
<b>Externalization mode</b>	Terminal	114	74.5
	Two mouths	11	7.2
	In loop	27	17.6
	Other	1	0.7
<b>Has pre-operative demarcation been performed?</b>	Yes	20	13.1
	No	133	86.9
<b>Abdominal location</b>	Upper right quadrant	12	7.8
	Upper left quadrant	18	11.9
	Lower right quadrant	44	28.7
	Lower left quadrant	79	51.6
<b>Shape of the stoma</b>	Circular	60	39.2
	Oval	93	60.8
<b>Stoma</b>	Protruding	99	64.7
	Flat	40	26.1
	Retracted	14	9.2
<b>Shape</b>	Regular	110	71.9
	Irregular	43	28.1
<b>Effluent</b>	Mucus	2	1.3
	Liquid	17	11.1
	Semi-liquid	20	13.1
	Pasty	84	54.9
	Well-formed	16	10.5
	Others	14	9.1
<b>Complications*</b>	None	114	74.5
	Edema	8	5.2
	Bleeding	16	10.5
	Retraction	9	5.9
	Infection	33	21.6
	Prolapse	12	7.8
	Others	3	2.0
<b>Peristomal skin*</b>	Intact	93	60.8
	Hyperemia	28	18.3
	Dermatitis	35	22.8
	Epithelioid granuloma	20	13.1
	Others	7	4.6
<b>Hygiene</b>	Good	126	82.4
	Satisfactory	23	15.0
	Deficient	4	2.6
<b>Total</b>		<b>153</b>	<b>100</b>

**Note:** \*The sum of the frequencies is greater than 100% because the participant may have manifested more than one complication/peristomal skin.

It is observed that 69 reported colorectal cancer as the main cause for the ostomies (45.1%), 139 walked (90.9%), 105 had colostomies (68.3%), 79 had temporary stomas (51.6%), and 114 had terminal externalization stomas (74.5%). In addition to that, 79 had stomas located in the lower left quadrant (51.6%) and 133 asserted that no demarcation was performed in the pre-operative period (86.9%).

Regarding the stomas, 99 had protrusions (64.7%), 93 were oval in shape (60.8%), 110 had a regular shape (71.9%), 84 drained pasty feces (54.9%), 126 showed good hygiene (82.3%), 114 presented no complications in the stoma (74.5%) and 93 showed intact peristomal skin (60.7%).

When assessing adaptation, there were more (64.7%) people totally adapted to the new condition, performing emptying of the collecting equipment (68.6%), drying the peristomal skin (64.0%), cleaning the stoma (64.7%), detaching the equipment (57.5%), measuring the stoma (53.6%) and making the mold (52.9%) on their own.

Table 2 presents the results of the analyses related to the association between the self-care variables.

**Table 2:** Association between the variables related to the self-care practice and self-care performance in people with elimination ostomies. Teresina, PI, Brazil, 2023.

Variables	n	Self-care performance			p-value
		On their own n (%)	With help n (%)	Caregiver n (%)	
<b>Emptying the collecting equipment</b>					<b>&lt;0.001<sup>a</sup></b>
On their own	105 (68.63)	80 (100.00)	24 (61.54)	1 (2.94)	
With help	15 (9.80)	0 (0.0)	14 (35.90)	1 (2.94)	
In charge of the caregiver	33 (21.57)	0 (0.0)	1 (2.56)	32 (94.12)	
<b>Cleaning the stoma</b>					<b>&lt;0.001<sup>a</sup></b>
On their own	99 (64.71)	80 (100.00)	19 (48.72)	0 (0.0)	
With help	18 (11.76)	0 (0.0)	16 (41.03)	2 (5.88)	
In charge of the caregiver	36 (23.53)	0 (0.0)	4 (10.26)	32 (94.12)	
<b>Drying the peristomal skin</b>					<b>&lt;0.001<sup>a</sup></b>
On their own	98 (64.05)	80 (100.00)	18 (46.15)	0 (0.0)	
With help	17 (11.11)	0 (0.0)	15 (38.46)	2 (5.88)	
In charge of the caregiver	38 (24.84)	0 (0.0)	6 (15.38)	32 (94.12)	
<b>Detaching the equipment</b>					<b>&lt;0.001<sup>a</sup></b>
On their own	88 (57.52)	80 (100.00)	6 (15.38)	2 (5.88)	
With help	18 (11.76)	0 (0.0)	17 (43.59)	1 (2.94)	
In charge of the caregiver	47 (30.72)	0 (0.0)	16 (41.03)	31 (91.18)	
<b>Measuring the stoma</b>					<b>&lt;0.001<sup>a</sup></b>
On their own	82 (53.59)	79 (98.75)	3 (7.69)	0 (0.0)	
With help	16 (10.46)	0 (0.0)	15 (38.46)	1 (2.94)	
In charge of the caregiver	55 (35.95)	1 (1.25)	21 (53.85)	33 (97.06)	
<b>Making the mold</b>					<b>&lt;0.001<sup>a</sup></b>
On their own	81 (52.94)	79 (98.75)	2 (5.13)	0 (0.0)	
With help	18 (11.76)	0 (0.0)	17 (43.59)	1 (2.94)	
In charge of the caregiver	54 (35.30)	1 (1.25)	20 (51.28)	33 (97.06)	
<b>Total</b>		<b>80 (100)</b>	<b>39 (100)</b>	<b>34 (100)</b>	

<sup>a</sup> - Chi-square test

The “emptying the collecting equipment” ( $p < 0.001$ ), “cleaning the stoma” ( $p < 0.001$ ), “drying the peristomal skin” ( $p < 0.001$ ), “plaque detachment” ( $p < 0.001$ ), “measuring the stoma” ( $p < 0.001$ ) and “making the mold” ( $p < 0.001$ ) variables showed a significant association with self-care.

Table 3 shows the results of the analyses related to the association between the variables of adaptation, pre- and post-operative guidance, social and sexual image and self-care.

**Table 3:** Association between the variables of adaptation, pre- and post-operative guidance, social and sexual image and self-care in people with elimination ostomies. Teresina, PI, Brazil, 2023.

Variables	n(%)	Self-care performance			p-value
		On their own	With help	Caregiver	
	n(%)	n(%)	n(%)	n(%)	
<b>Adaptation of the person with an ostomy to the new condition</b>					<b>&lt;0.001<sup>a</sup></b>
Not adapted	18 (11.76)	2 (2.50)	4 (10.26)	12 (35.29)	
Partially adapted	36 (23.53)	15 (18.75)	12 (30.77)	9 (26.47)	
Totally adapted	99 (64.71)	63 (78.75)	23 (58.97)	13 (38.24)	
<b>Received pre-operative guidance</b>					0.682 <sup>a</sup>
Yes	85 (55.56)	43 (53.75)	24 (61.54)	18 (52.94)	
No	68 (44.44)	37 (46.25)	15 (38.46)	16 (47.06)	
<b>Received guidance after hospital discharge</b>					0.918 <sup>a</sup>
Yes	128 (83.66)	66 (82.50)	33 (84.62)	29 (85.29)	
No	25 (16.34)	14 (17.50)	6 (15.38)	5 (14.71)	
<b>Decreased self-esteem</b>					<b>0.034<sup>a</sup></b>
Yes	93 (60.78)	41 (51.25)	29 (74.36)	23 (67.65)	
No	60 (39.22)	39 (48.75)	10 (25.64)	11 (32.35)	
<b>Social isolation</b>					<b>0.020<sup>a</sup></b>
Yes	87 (56.86)	37 (46.25)	26 (66.67)	24 (70.59)	
No	66 (43.14)	43 (53.75)	13 (33.33)	10 (29.41)	
<b>Sexual performance</b>					<0.391 <sup>a</sup>
Yes	62 (40.52)	29 (36.25)	16 (41.03)	17 (50.00)	
No	91 (59.48)	51 (63.75)	23 (58.97)	17 (50.00)	
<b>Total</b>		<b>80 (100)</b>	<b>39 (100)</b>	<b>34 (100)</b>	

Note: <sup>a</sup> - Chi-square test

In relation to the psychosocial changes, it was evidenced that there was a decrease in self-esteem (69.8%) and an increase in social isolation (56.9%) after the stoma was created; however, most of the participants did not have their sexual performance affected (59.48%). In addition to that, it was verified that more people performed self-care on their own (52.3%), followed by those who did so with help (25.5%) and those who needed help from their caregivers (22.2%). A significant association was observed between the self-care variable and the adapted ( $p<0.001$ ), emptying the collection equipment ( $p<0.001$ ), self-esteem ( $p=0.034$ ) and social isolation ( $p=0.020$ ) variables.

## DISCUSSION

The results of this study are similar to those of other studies on people with stomas<sup>5,9,13-14</sup>, where the majority of people with stomas were male, married, with Elementary School, retired and earning incomes of up to two minimum wages. The prevalence of colostomy in the study participants is directly linked to the cause of the stoma, with colorectal cancer as the main factor that leads to performing a stoma<sup>5,9,13-19</sup>.

Regarding the characteristics of the stoma, this study corroborates previous ones that showed predominance of colostomies, located in the lower left quadrant, with a protruding shape and terminal externalization, with predominance of temporary ostomies of a regular shape and with pasty effluents<sup>14,19-21</sup>.

Carrying out the demarcation during the pre-operative period is a clinical and scientific recommendation, although there is no significant correlation with self-care in this research. It is important to note that demarcation of the ostomy exerts a significant impact on self-care in terms of hygiene, adaptation and adherence to the collecting equipment, in addition to preventing leaks of effluents to the peristomal skin, thus avoiding possible complications. However, in this study it was evidenced that most people did not undergo ostomy demarcation before surgery<sup>17,19,22</sup>.

Emptying, cleaning, drying the peristomal skin, detachment, measuring the collecting equipment and making the mold were considered as factors associated with self-care. The literature presents hygiene, peristomal skin care, clipping and fixation of the collecting equipment as difficulties for people with ostomies, due to the need for manual skills<sup>5,23</sup>. Thus, we emphasize the need for health education aimed at people with elimination ostomies and caregivers, starting from the first visit, in order to reduce the self-care deficit and improve these patients' adaptation and quality of life<sup>6</sup>.

In this sense, it is relevant that health teams promote educational actions throughout the peri-operative period, from pre-operative actions, when the previous skills of patients and families will be evaluated, to the post-operative period. It is also crucial to consider all psychological, social and physical aspects of people with elimination ostomies in order to develop an adequate plan for maintaining care<sup>5</sup>.

Therefore, adaptation is a relevant factor, as the impairment of aspects related to self-care can negatively influence this process. The consequences that this surgical intervention has on personal, emotional and professional life result in insecurity during the stoma care stages. Therefore, it is crucial that health professionals improve their knowledge on the topic to offer personalized care, aiming at patient safety and easing their adaptation to the new reality experienced<sup>24,25</sup>.

The initial process of adaptation to the stoma is considered individual, and each person has its own time for acceptance, adaptation and reformulation of life, according to their needs. Self-care is considered indispensable for physical and psychosocial adaptation. Therefore, to be achieved, this process must be collective, with the participation of patients, family members and health professionals, taking into account the social context<sup>13,26</sup>.

The changes in everyday life resulting from performing an ostomy generate changes in the routine and body changes related both to the image and to the physiology of this population segment. The acceptance process requires an adaptation to the collecting equipment and to a new care and hygiene routine. However, these changes can negatively affect people with elimination ostomies, in addition to being able to reverberate in social isolation<sup>6</sup>.

Decreased self-esteem and social isolation presented a statistically significant association with self-care in this study. Performing an ostomy can generate negative feelings related to body image and self-esteem, mainly compromising these people's quality of life<sup>26</sup>. Self-esteem impairment and social isolation cause significant changes in interpersonal relationships, which further compromises the adaptation process and the performance of daily activities<sup>15</sup>.

In this context, the presence of the partner is seen as an important emotional support and assists in adapting and coping with the difficulties that arise with the ostomy, in the role of cooperator and encourager in performing the care measures<sup>24,27</sup>.

When effective, self-care contributes to human growth; however when limited, a deficit arises, which indicates the need for Nursing actions<sup>28</sup>. In light of Dorothea Orem's Theory, Nursing will need to identify self-care deficits and define support modalities. In this way, it can develop adequate care for people with ostomies, seeking to turn patients into self-care agents, reduce complications and achieve their social reintegration<sup>29</sup>.

Orem's self-care theory emphasizes that, once empowered, people must take care of themselves; in other words, self-care consists of a set of actions that the population performs to maintain their lives. In addition to that, in Nursing care, it is fundamental to observe people's learning ability and the deficits evidenced. In this sense, nurses' role is essential for people with ostomies to achieve their independence in relation to self-care<sup>30</sup>.

At the specialized center where this study was conducted, it was verified that the participants received frequent guidelines and support from nurses regarding self-care. It is worth noting that the service is an internship field of Nursing specialization in Stomatherapy and has stomatherapists to perform Nursing consultations for people with elimination ostomies.

Stomatherapy Nursing consultations offer care in a differentiated way, easing care continuity through personalized monitoring and support to people with ostomies in the different adaptation phases to their new life condition, solving underlying problems, assisting them and the family in rehabilitation and obtaining the best quality of life possible<sup>31</sup>. Previous studies, which evaluated the care provided in Stomatherapy Nursing consultations, proved that the consultations with stomatherapists had lower rates of stoma complications and lower anxiety in the post-operative period<sup>31,32</sup>.

This reflection shows that, when associated with theory, Nursing care can result in more effective assistance for people with ostomies, encouraging this population group to participate more in their care plan. With regard to the patients' knowledge, their post-ostomy condition and interventional factors are fundamental to overcome several challenges that will arise during the care offered to this population segment<sup>29</sup>.

### Study limitations

The study limitations refer to its design, which does not allow establishing a cause-and-effect relationship, as well as to the absence of many people with ostomies registered in the service that live in the inland of the state, either due to the access difficulty or the brief data collection period, compromising sample homogeneity and representativeness.



With the results obtained, it is expected to contribute to the elaboration of strategies that guide future interventions to improve the self-care of patients with elimination ostomies and the support to their caregivers, in addition to collaborating with the reduction of social barriers and to improving care for this population group, as well as cooperating with the permanent education of health professionals focused on care integrality for people with elimination ostomies.

## CONCLUSION

This study identified that emptying the collecting equipment, cleaning the stoma, drying the peristomal skin, detaching the plaque, measuring the stoma, making the mold, adapting to the new condition, decreased self-esteem and social isolation were associated with self-care, which highlights the importance of health education aimed at self-care for people with elimination ostomies, family members and/or caregivers.

It was observed that most of the people with elimination ostomies were adapted to the new reality and performed self-care practices on their own. However, it was noticed that changes in body image exerted negative impacts on people with elimination ostomies, causing a decrease in self-esteem and generating social isolation, which directly influenced the self-care process. Thus, Nursing care for people with elimination ostomies with a focus on self-care is fundamental to assist in devising strategies to adapt the users to their new condition, preventing complications and providing better quality of life.

Therefore, the need for new research studies that evaluate the patients' knowledge about self-care practices during all adaptation stages is emphasized, in order to implement effective lines of care and public health policies that may contribute to comprehensive care for people with elimination ostomies, in order to improve self-care and allow greater autonomy to the patients.

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Conceptualization, ACO, LTN, LKAO, GFR, JACL, CDAV e AMGB; methodology, ACO, LKAO e GFR; formal analysis, ACO; investigation, ACO, LKAO e GFR; resources, ACO, LKAO e GFR; data curation, ACO, LTN, LKAO e GFR; manuscript writing, ACO, LTN, LKAO e GFR; manuscript review and editing, JACL, CDAV, AMGB; visualization, ACO, LTN, LKAO, GFR, JACL, CDAV e AMGB; supervision, LTN; project administration, ACO; financial support, not applied. All authors have read and agreed to the published version of the manuscript.