

Survey on Actual Status of Difficulties
Experienced by Ostomates 2020

What We Want You to Know Living with a Stoma

NPO Stoma Image Up Project



Introduction

Five years have passed since “Report of Survey on Actual Status of Difficulties Experienced by Ostomates” (survey in 2011) was issued in 2015. During the period, not only healthcare professionals but also many other people have used the survey results, and we have received requests for continuation of the survey. We, NPO Stoma Image Up Project (SIUP), decided to conduct the “Survey on Actual Status of Difficulties Experienced by Ostomates” again in 2017, five years after the previous survey, because the purpose of our activities is to ensure that stoma is recognized correctly by the general public and healthcare professionals, and we believe it is our most important mission to provide information on the real picture of ostomates reflecting the changes in medical care and society. In this survey, problems anticipated in disastrous situations and difficulties associated with aging were added to the previous survey topics.

We sincerely hope that the results of this survey will be useful to help many both current and future ostomates, families and friends supporting them, people, healthcare professionals and government officials engaging in services associated with stoma.

Lastly, we would like to express our gratitude to the ostomates and their families who cooperated in this survey, and to those who have encouraged us, NPO SIUP.

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* The percentages in the tables in this survey are calculated to the second decimal place and rounded to the nearest figures.

I. Overview of Questionnaire Survey

1. Survey period

April 1, 2017 to March 31, 2018

2. Respondents

3,000 ostomates aged 20 years and older who purchased the ostomy appliance at ostomy appliance dealers

3. Survey method

Self-administered semi-structured questionnaire survey by mail

4. Ethical considerations for questionnaire survey

The survey was approved by the ethical review board of Osaka University Hospital.

5. Status of collection

The number of questionnaire distributed was 3,000, and the number of questionnaire collected was 1,087 (collection rate: 36.2%). Of the 1,087 sheets, 1 sheet with incomplete description was excluded, and 1,086 sheets were included in the analysis. (valid response rate: 36.2%)

II. Tabulation of Results

The results are tabulated according to the questionnaire for the “Survey on Actual Status of Difficulties Experienced in Social Life and Consultations by Ostomates.”

Background of Respondents

1. Age of respondents

	Actual number	(%)
1. 20s	6	0.6
2. 30s	13	1.2
3. 40s	45	4.1
4. 50s	104	9.6
5. 60s	320	29.5
6. 70s	369	34.0
7. 80s	188	17.3
8. 90s	27	2.5
9. No response	14	1.3
Total	1086	100.0

The most common age group was 70s, followed by 60s and 80s. Respondents in their 60s or older accounted for 85% of all respondents.

2. Gender

	Actual number	(%)
1. Female	436	40.1
2. Male	640	58.9
3. No response	10	0.9
Total	1086	100.0

3. Types of stoma

	Actual number	(%)
1. Colostomy	603	55.5
2. Ileostomy	113	10.4
3. Gastrointestinal stoma (site unknown)	76	7.0
4. Urostomy	203	18.7
5. Double stoma	30	2.8
6. Other	7	0.6
7. No response	54	5.0
Total	1086	100.0

Colostomy was most common, followed by urostomy and ileostomy in this order. A total of 73% of the respondents, including those who answered that they were not sure whether colostomy or ileostomy, had gastrointestinal stoma.

* Double stoma: Those who have both gastrointestinal stoma and urostomy

4. Kind of stoma

	Actual number	(%)
1. Permanent stoma	753	69.3
2. Temporary stoma	157	14.5
3. Both permanent and temporary	1	0.1
4. Unknown	118	10.9
5. No response	57	5.2
Total	1086	100.0

The permanent stoma accounted for approximately 70%.

5. Duration of stoma

	Actual number	(%)
1. Less than 6 months	90	8.3
2. 6 months to less than 1 year	129	11.9
3. 1 to 3 years	297	27.3
4. 4 to 5 years	135	12.4
5. 6 to 10 years	195	18.0
6. 11 years or longer	225	20.7
7. No response	15	1.4
Total	1086	100.0

Less than 1 year in 20%, 1 to 5 years in 40%, 6 to 10 years in 18%, and 11 years or longer in 21%.

1) Duration of stoma by types of stoma

[1] Colostomy

	Actual number	(%)
1. Less than 1 year	110	18.2
2. 1 to 5 years	251	41.6
3. 6 to 10 years	110	18.2
4. 11 years or longer	131	21.7
5. No response	1	0.2
Total	603	100.0

[2] Ileostomy

	Actual number	(%)
1. Less than 1 year	47	41.6
2. 1 to 5 years	25	22.1
3. 6 to 10 years	17	15.0
4. 11 years or longer	24	21.2
5. No response	0	0.0
Total	113	100.0

[3] Urostomy

	Actual number	(%)
1. Less than 1 year	29	14.3
2. 1 to 5 years	89	43.8
3. 6 to 10 years	43	21.2
4. 11 years or longer	41	20.2
5. No response	1	0.5
Total	203	100.0

[4] Double stoma

	Actual number	(%)
1. Less than 1 year	1	3.3
2. 1 to 5 years	12	40.0
3. 6 to 10 years	6	20.0
4. 11 years or longer	11	36.7
5. No response	0	0.0
Total	30	100.0

6. Occupation

	Actual number	(%)
1. Yes	302	27.8
2. No	747	68.8
3. No response	37	3.4
Total	1086	100.0

Approximately 69% of respondents had no occupation.

7. Status of visit to outpatient ostomy clinic

	Actual number	(%)
1. Visit regularly.	500	46.0
2. Visit only when having a problem.	221	20.3
3. Do not visit at present.	216	19.9
4. Have never visited.	129	11.9
5. No response	20	1.8
Total	1086	100.0

A total of 86% of the respondents have ever visited the outpatient ostomy clinic. The percentage of respondents who were visiting the clinic continuously was 66%.

1) Visit to outpatient ostomy clinic by types of stoma

[1] Colostomy

		Actual number	(%)
1.	Visit regularly.	254	42.1
2.	Visit only when having a problem.	126	20.9
3.	Do not visit at present.	134	22.2
4.	Have never visited.	80	13.3
5.	No response	9	1.5
Total		603	100.0

[2] Ileostomy

		Actual number	(%)
1.	Visit regularly.	53	46.9
2.	Visit only when having a problem.	32	28.3
3.	Do not visit at present.	14	12.4
4.	Have never visited.	12	10.6
5.	No response	2	1.8
Total		113	100.0

[3] Urostomy

		Actual number	(%)
1.	Visit regularly.	111	54.7
2.	Visit only when having a problem.	29	14.3
3.	Do not visit at present.	38	18.7
4.	Have never visited.	21	10.3
5.	No response	4	2.0
Total		203	100.0

[4] Double stoma

		Actual number	(%)
1.	Visit regularly.	15	50.0
2.	Visit only when having a problem.	7	23.3
3.	Do not visit at present.	7	23.3
4.	Have never visited.	1	3.3
5.	No response	0	0.0
Total		30	100.0

2) Visit to outpatient ostomy clinic by duration of stoma

[1] Less than 1 year

		Actual number	(%)
1.	Visit regularly.	138	63.0
2.	Visit only when having a problem.	42	19.2
3.	Do not visit at present.	19	8.7
4.	Have never visited.	14	6.4
5.	No response	6	2.7
Total		219	100.0

[2] 1 to 5 years

		Actual number	(%)
1.	Visit regularly.	221	51.0
2.	Visit only when having a problem.	103	23.8
3.	Do not visit at present.	58	13.4
4.	Have never visited.	41	9.5
5.	No response	10	2.3
Total		433	100.0

[3] 6 to 10 years

		Actual number	(%)
1.	Visit regularly.	71	36.4
2.	Visit only when having a problem.	39	20.0
3.	Do not visit at present.	62	31.8
4.	Have never visited.	20	10.3
5.	No response	3	1.5
Total		195	100.0

[4] 11 years or longer

		Actual number	(%)
1.	Visit regularly.	62	27.6
2.	Visit only when having a problem.	36	16.0
3.	Do not visit at present.	73	32.4
4.	Have never visited.	54	24.0
5.	No response	0	0.0
Total		225	100.0

8. Prefecture of residence

	Actual number	(%)
1. Hokkaido	44	4.1
2. Iwate	2	0.2
3. Miyagi	71	6.5
4. Yamagata	4	0.4
5. Ibaraki	5	0.5
6. Tochigi	2	0.2
7. Gunma	1	0.1
8. Saitama	15	1.4
9. Chiba	51	4.7
10. Tokyo	131	12.1
11. Kanagawa	76	7.0
12. Niigata	3	0.3
13. Toyama	24	2.2
14. Ishikawa	37	3.4
15. Fukui	23	2.1
16. Gifu	24	2.2
17. Shizuoka	17	1.6
18. Aichi	30	2.8
19. Mie	6	0.6
20. Osaka	69	6.4
21. Hyogo	60	5.5
22. Nara	1	0.1
23. Okayama	30	2.8
24. Hiroshima	23	2.1
25. Yamaguchi	11	1.0
26. Tokushima	1	0.1
27. Kagawa	2	0.2
28. Ehime	43	4.0
29. Kochi	37	3.4
30. Fukuoka	11	1.0
31. Kumamoto	48	4.4
32. Oita	2	0.2
33. No response	182	16.8
Total	1086	100.0

9. Living place

	Actual number	(%)
1. Home	1037	95.5
2. Nursing facility	22	2.0
3. Medical institution	5	0.5
4. No response	22	2.0
Total	1086	100.0

96% of respondents were living at home.

Difficulties Experienced in Living with a Stoma

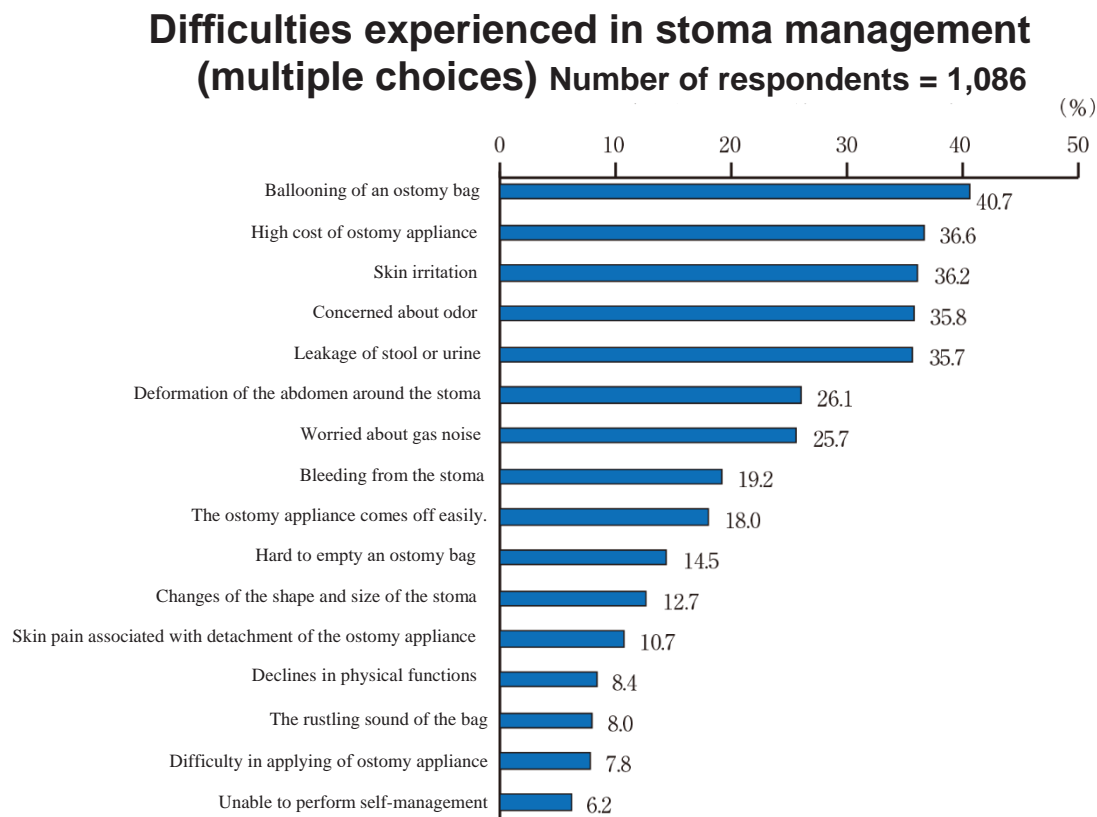
The difficulties experienced with the methods for stoma management in the past 6 months were classified into 3 categories: stoma management, daily life, and social life. Answers were asked for multiple choices.

1. Difficulties Experienced in Stoma Management

	Actual number	(%)
Having no experience of difficulty	124	11.4
Having experiences of difficulty	930	85.6
No response	32	2.9
Total	1086	100.0

The most common experience of difficulty in stoma management was “ballooning of an ostomy bag.”

The percentage of respondents who experienced difficulties was 86%.

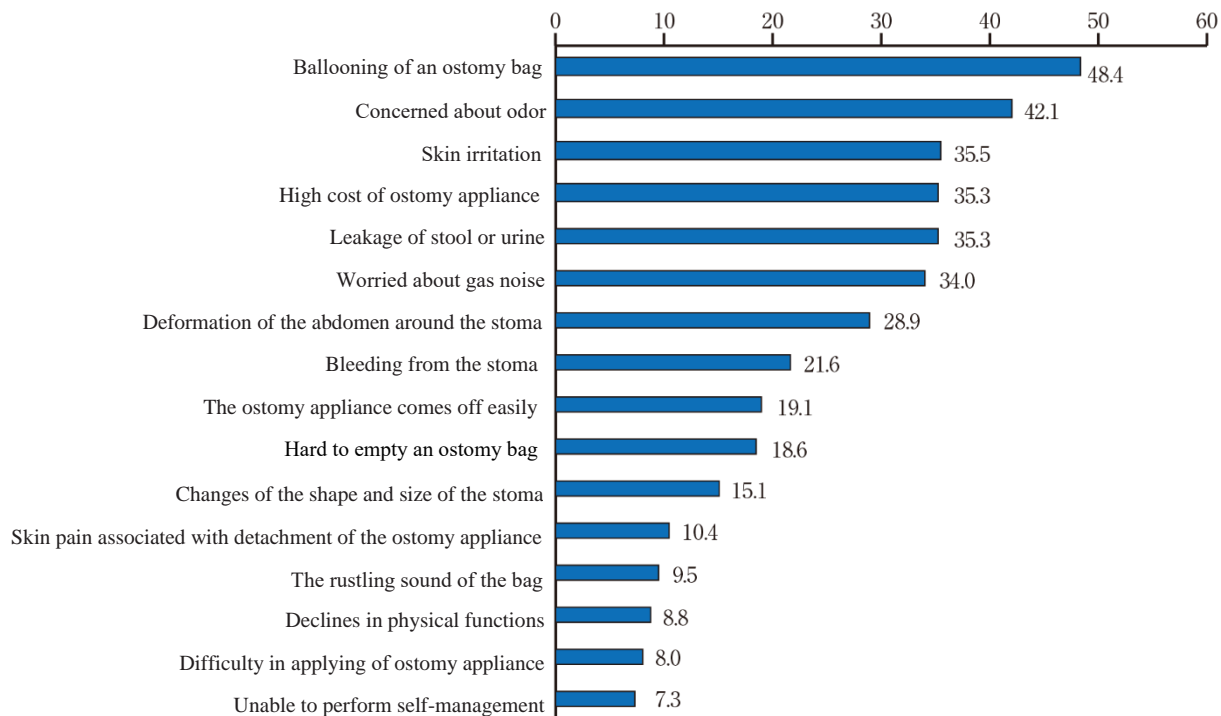


1) Difficulties experienced in stoma management classified by the types of stoma

“Ballooning of an ostomy bag” was the most common difficulty for colostomy, and “ballooning of an ostomy bag” and “skin irritation” were the most common difficulties for ileostomy, while “leakage of stool or urine” was the most common difficulty for urostomy.

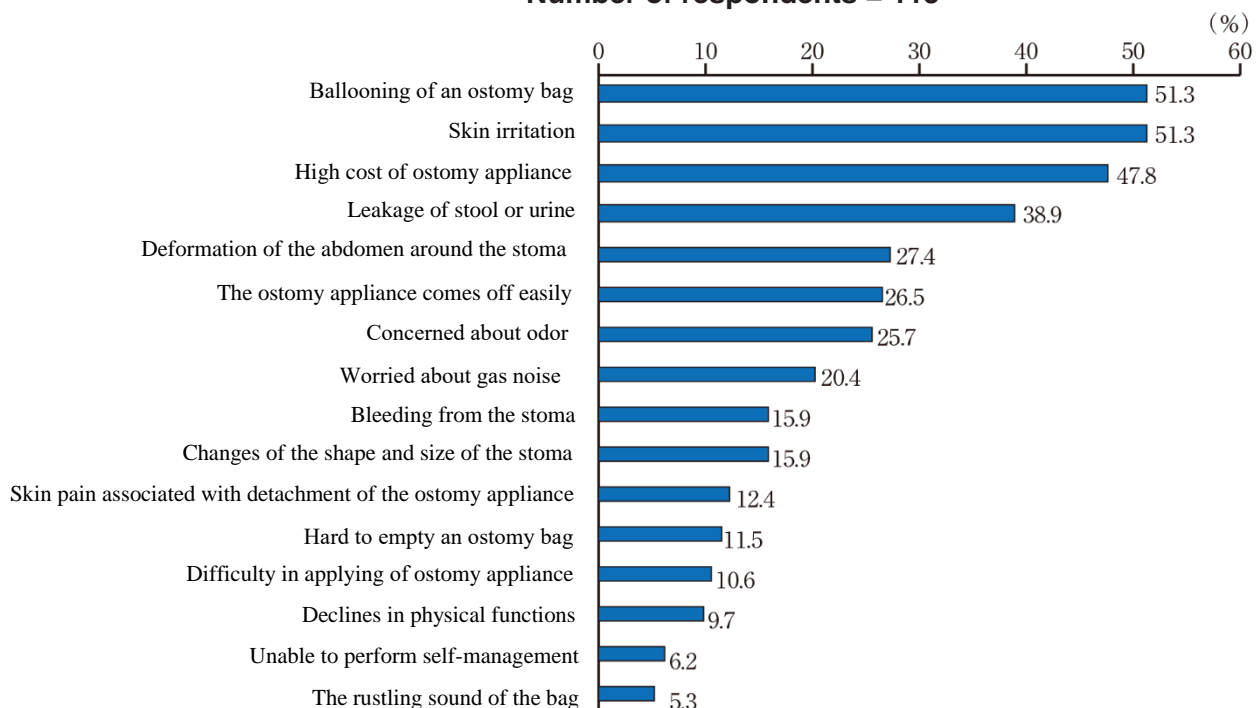
[1] Colostomy: Difficulties experienced in stoma management (multiple choices)

Number of respondents = 603

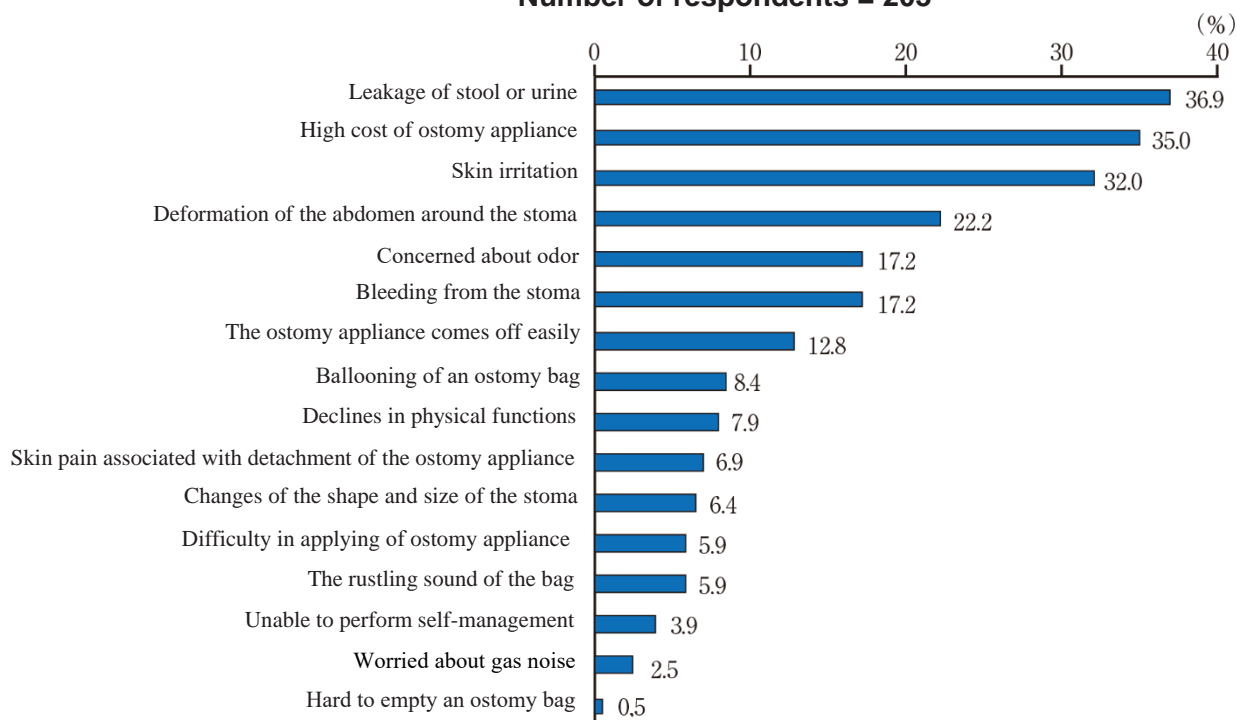


[2] Ileostomy: Difficulties experienced in stoma management (multiple choices)

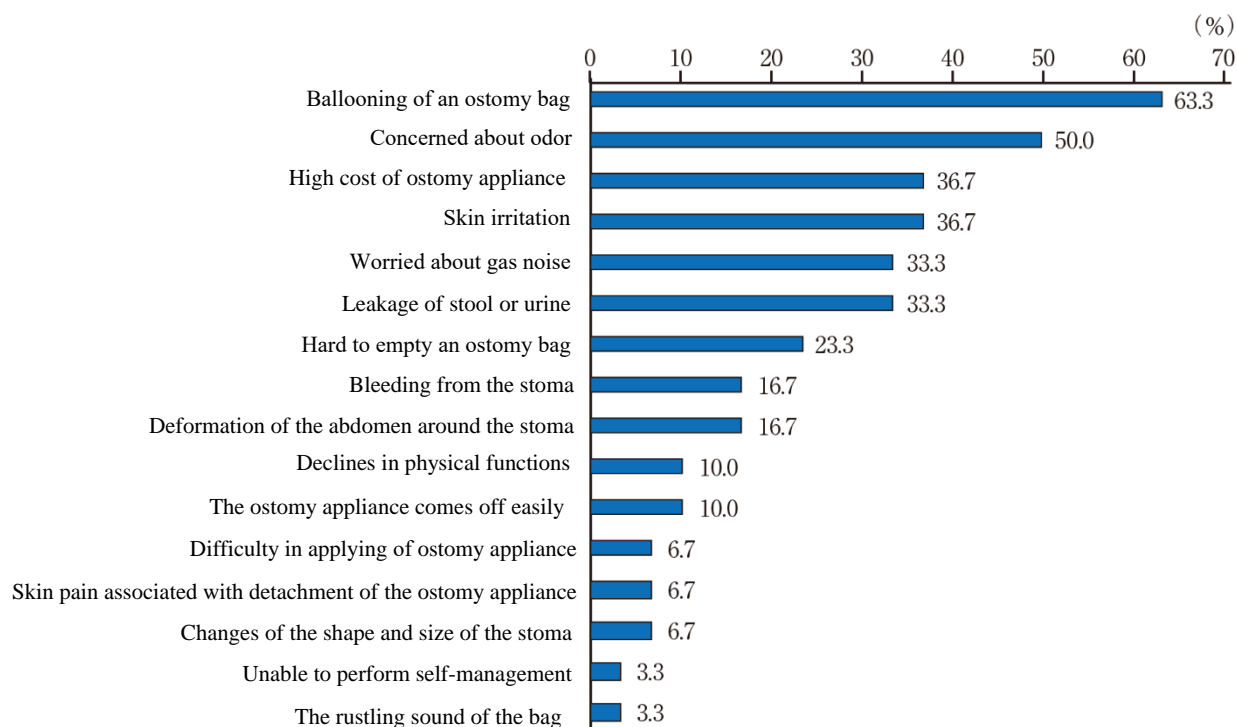
Number of respondents = 113



[3] Urostomy: Difficulties experienced in stoma management (multiple choices)
Number of respondents = 203



[4] Double stoma: Difficulties experienced in stoma management (multiple choices)
Number of respondents = 30

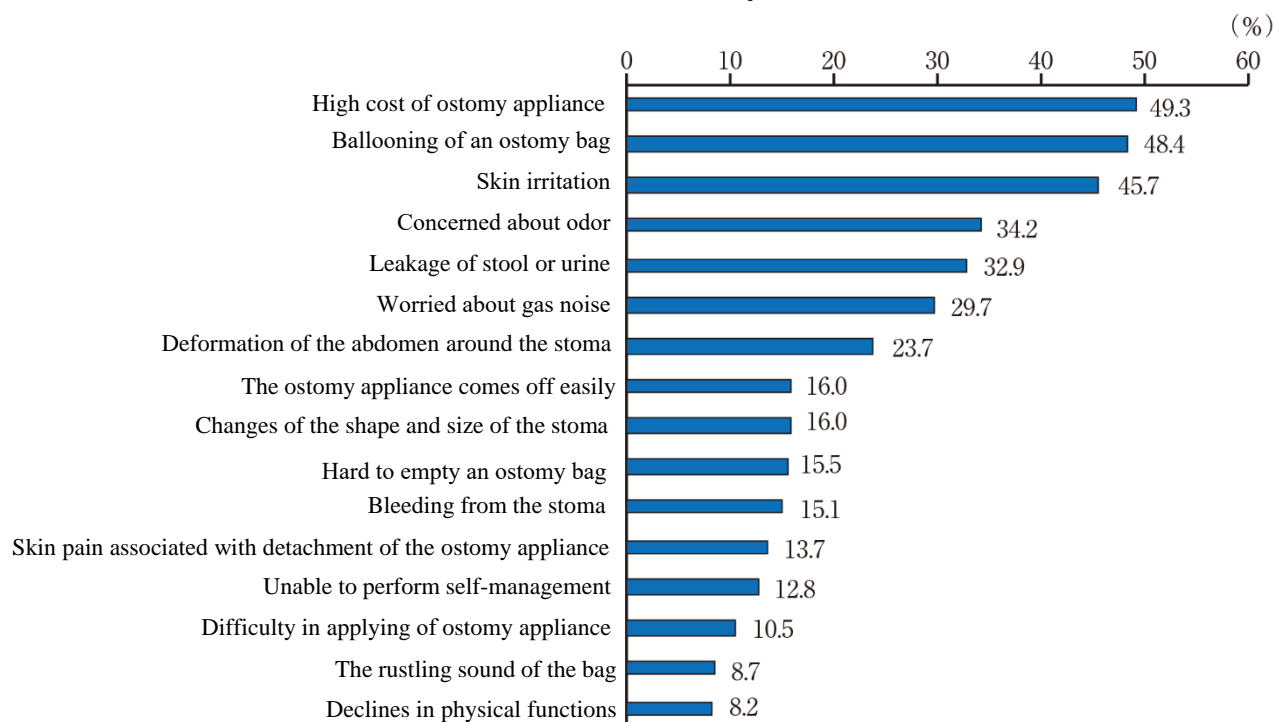


2) Difficulties experienced in stoma management classified by the duration of stoma

“Ballooning of an ostomy bag” was ranked high regardless of the duration.

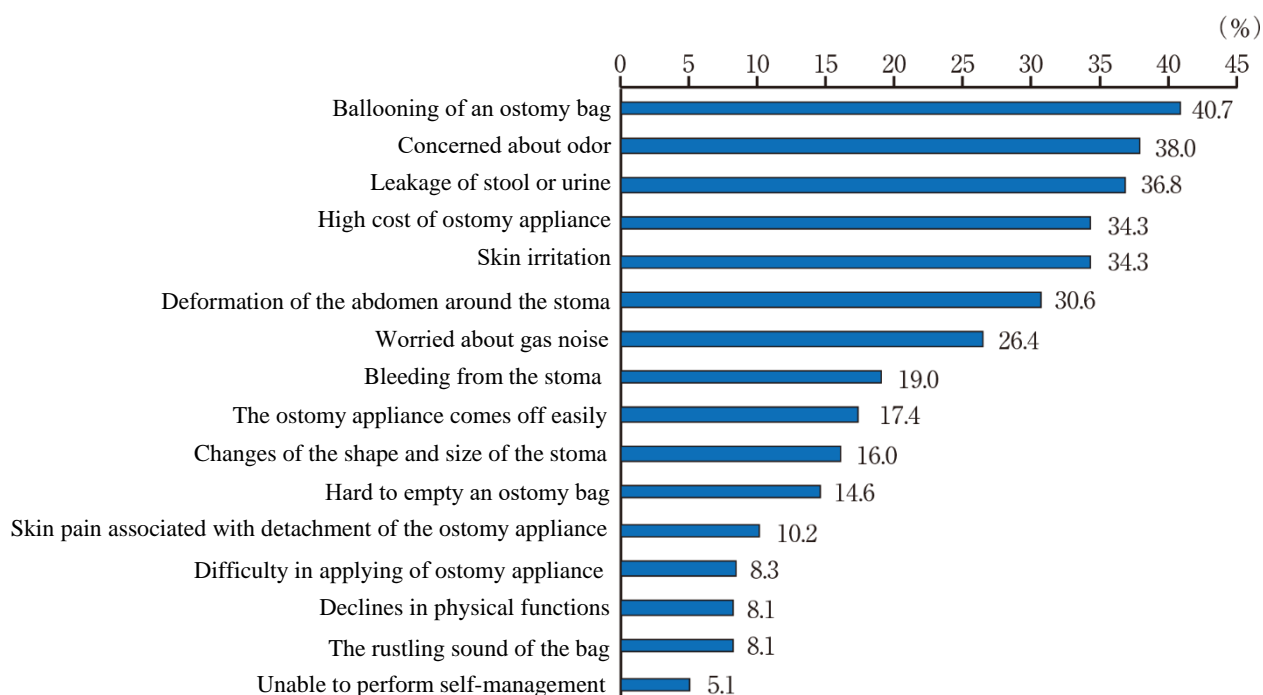
[1] Less than 1 year: Difficulties experienced in stoma management (multiple choices)

Number of respondents = 219



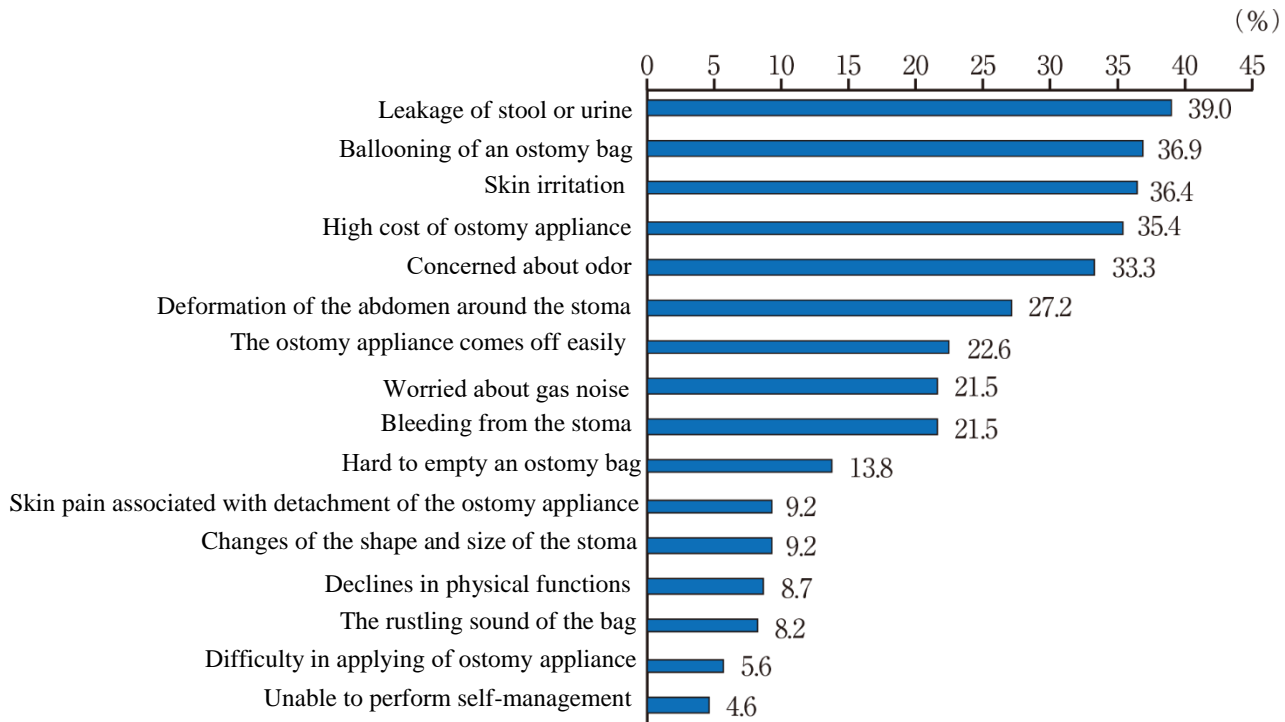
[2] 1 to 5 years: Difficulties experienced in stoma management (multiple choices)

Number of respondents = 432



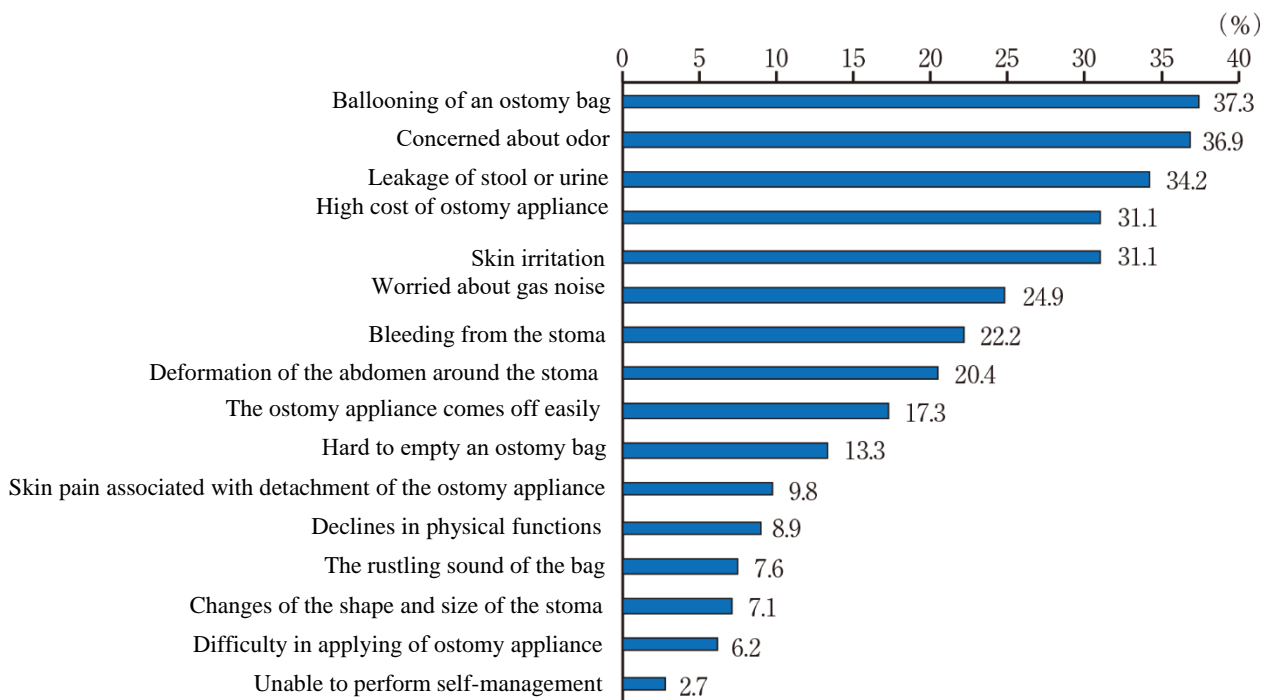
[3] 6 to 10 years: Difficulties experienced in stoma management(multiple choices)

Number of respondents = 195



[4] 11 years or longer: Difficulties experienced in stoma management (multiple choices)

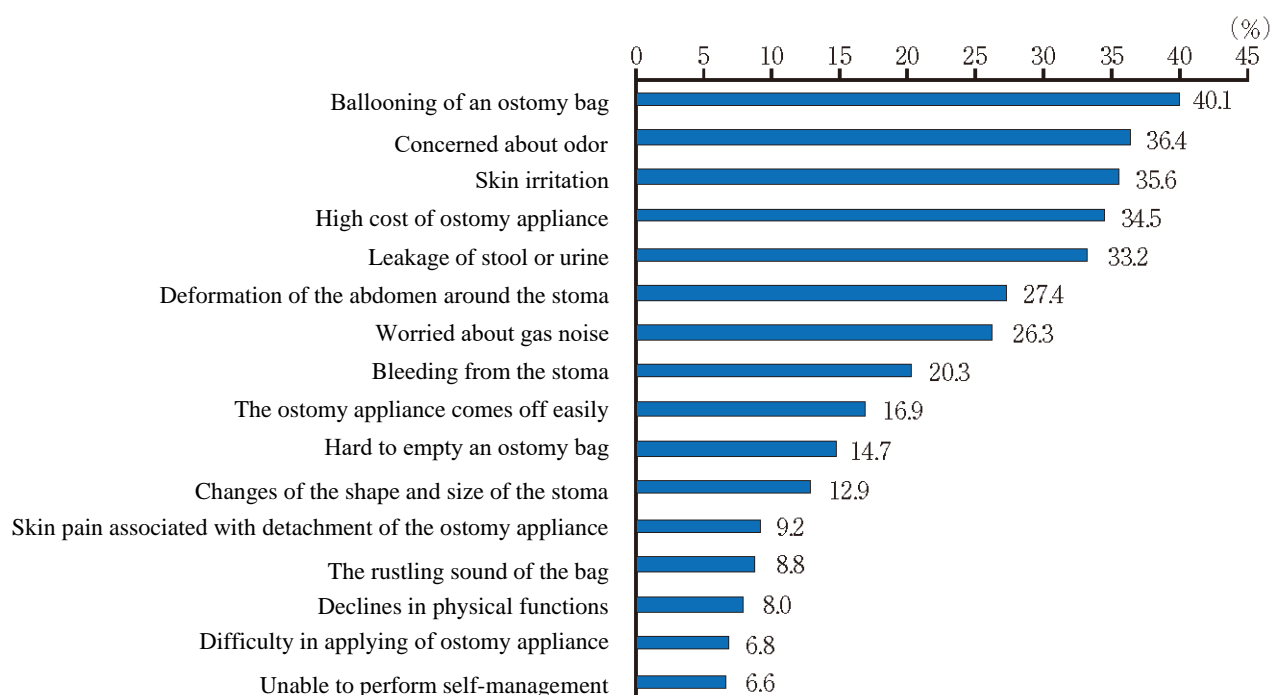
Number of respondents = 225



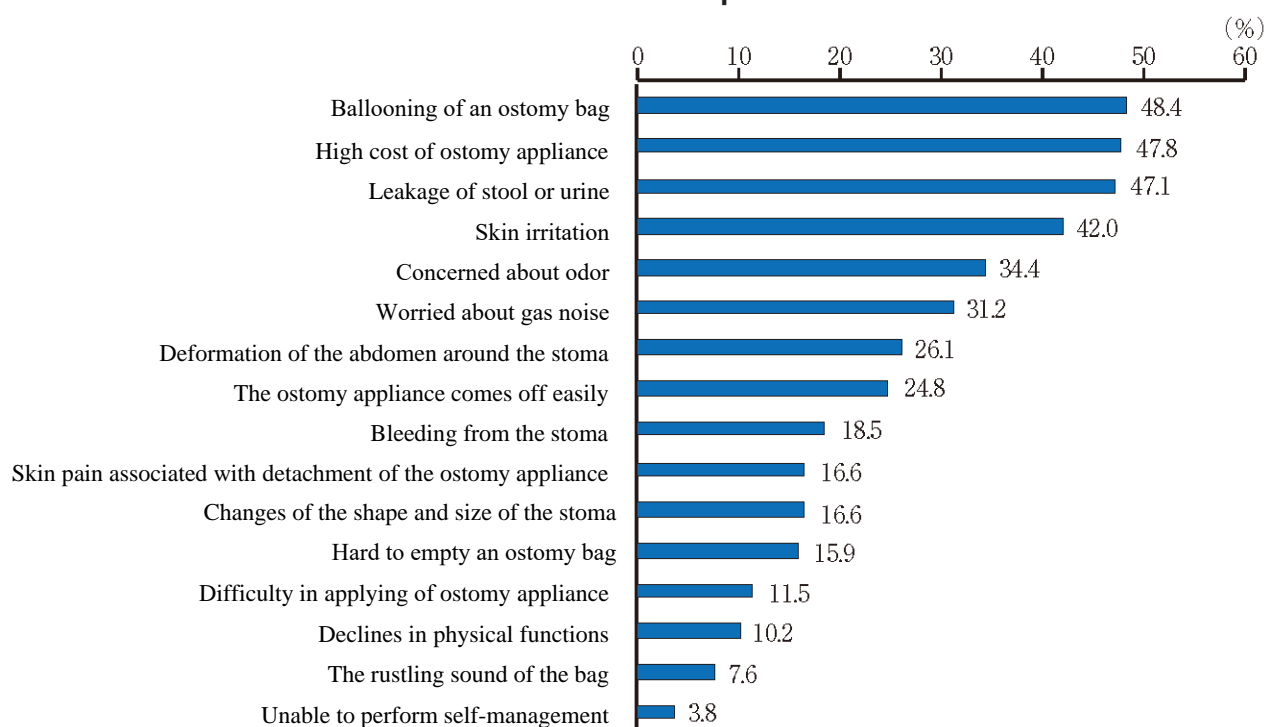
3) Difficulties experienced in stoma management permanent or temporary stoma

“Ballooning of an ostomy bag” was the most common difficulty for both permanent and temporary stomas. The next common difficulty was “concerned about odor” for the permanent stoma, and “high cost of ostomy appliance” for the temporary stoma.

[1] Permanent stoma: Difficulties experienced in stoma management(multiple choices) Number of respondents = 753



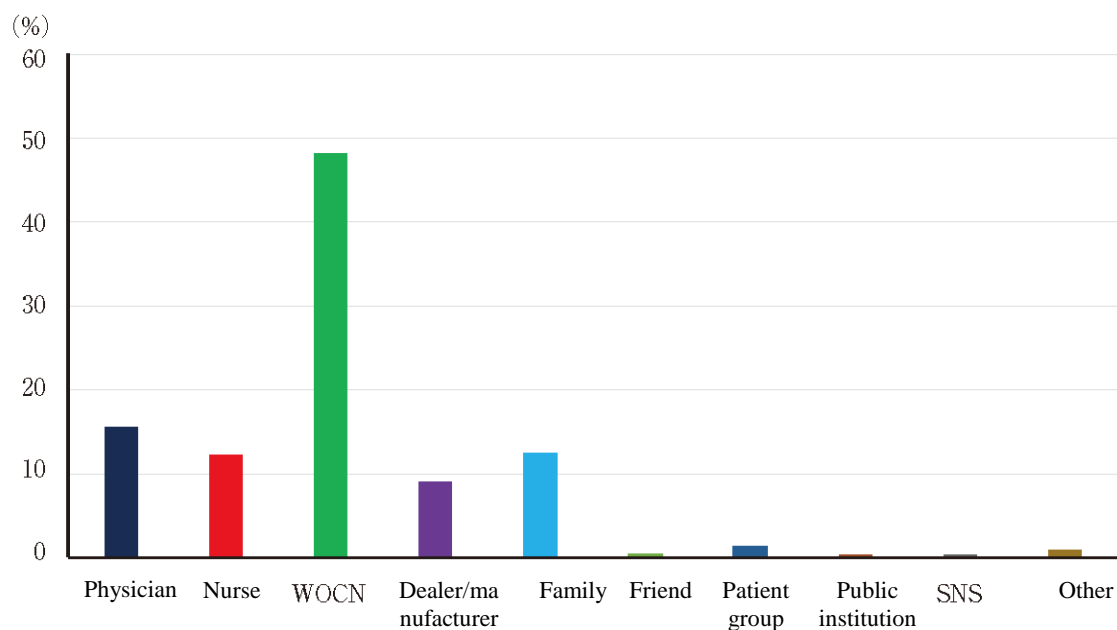
[2] Temporary stoma: Difficulties experienced in stoma management (multiple choices) Number of respondents = 157



4) Contacts for consultation made when having difficulties with stoma management

First priority contact made for consultation on stoma management

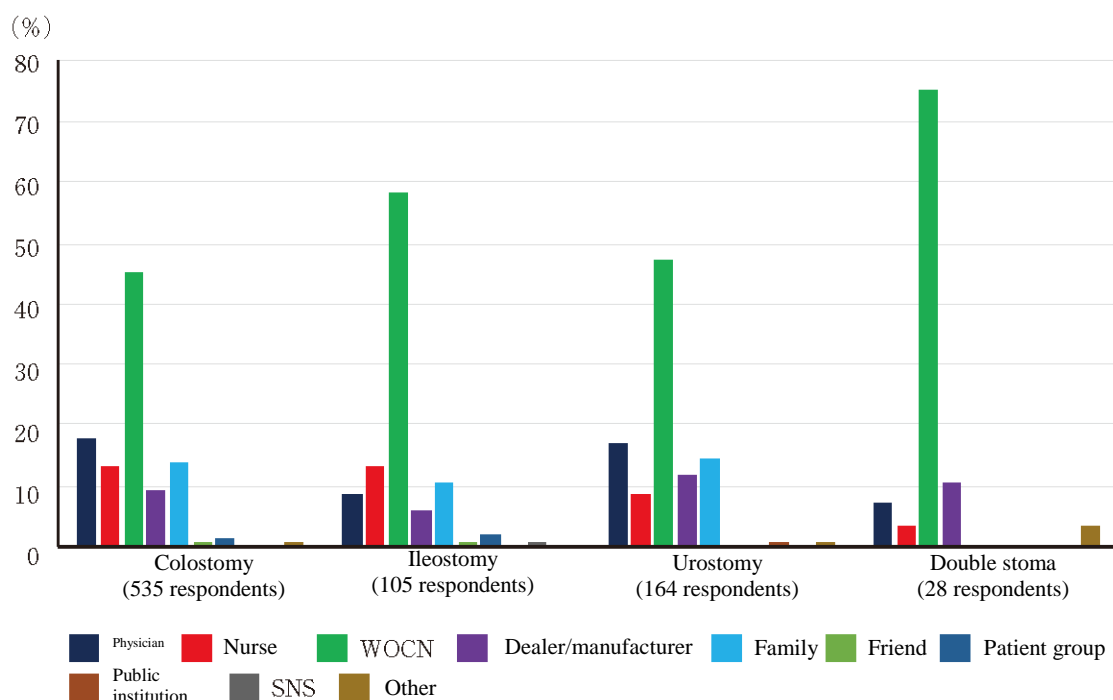
Number of respondents = 946



In each category, the WOC was the most preferred contact for consultation.

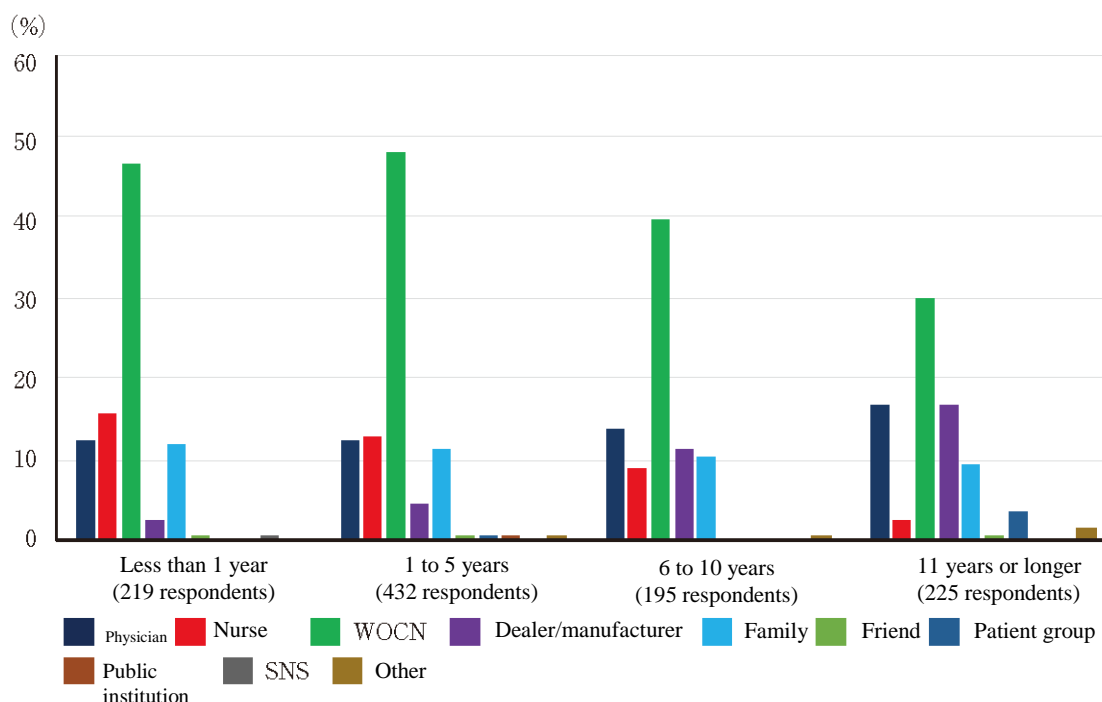
[1] Results by types of stoma (stoma management)

First priority contact made for consultation on stoma management



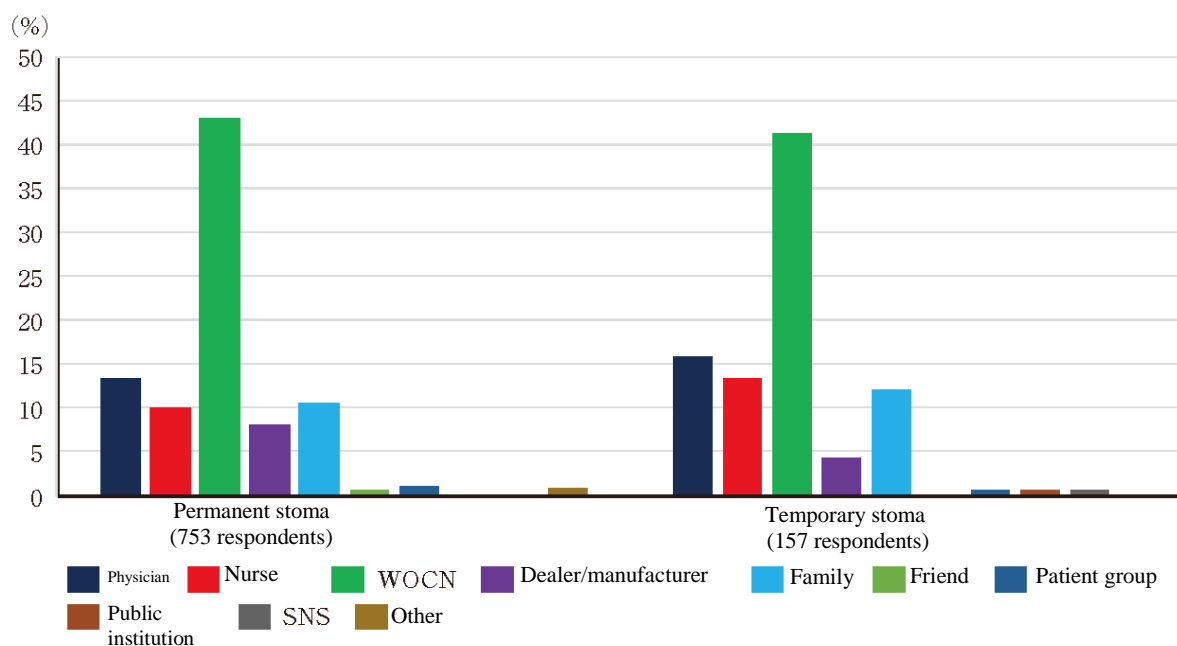
[2] Results by duration of stoma (stoma management)

First priority contact made for consultation on stoma management



[3] Results by permanent or temporary stoma (stoma management)

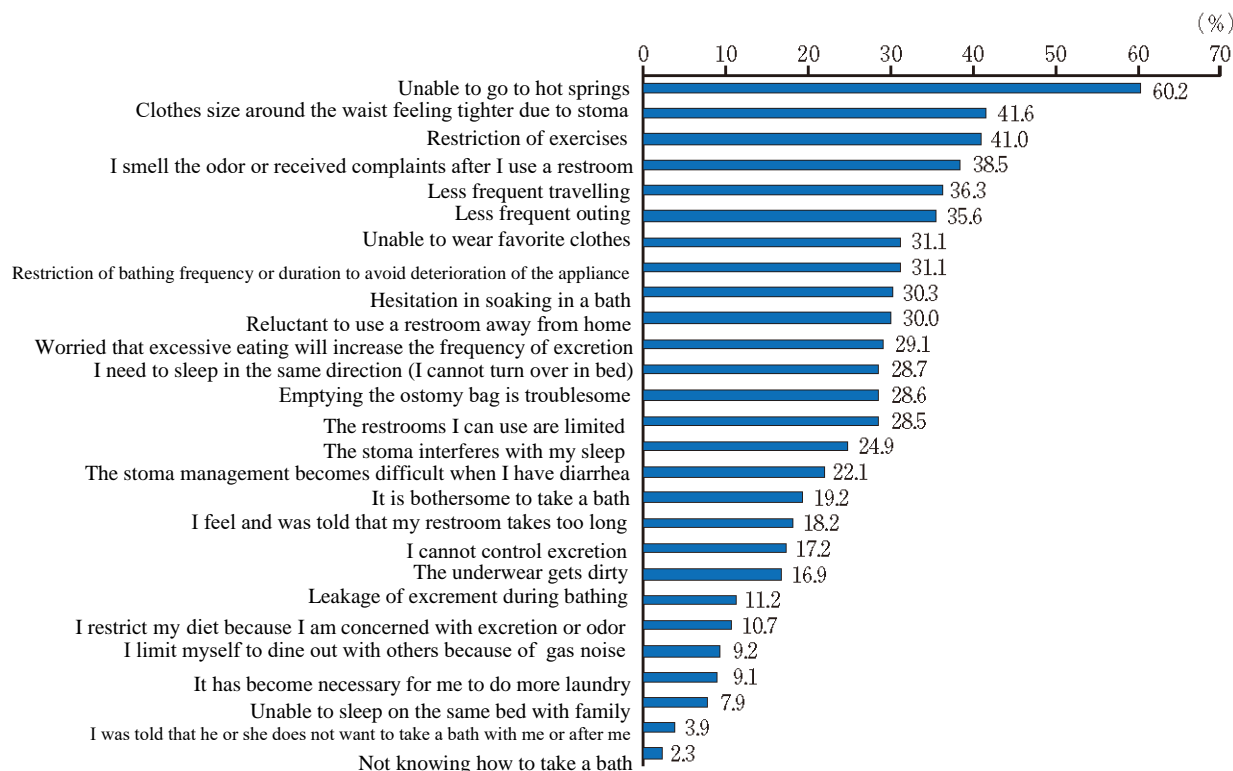
First priority contact for consultation on stoma management



2. Difficulties Experienced in Daily Life

The most common difficulty was “Unable to go to hot springs” regardless of the types of stoma.

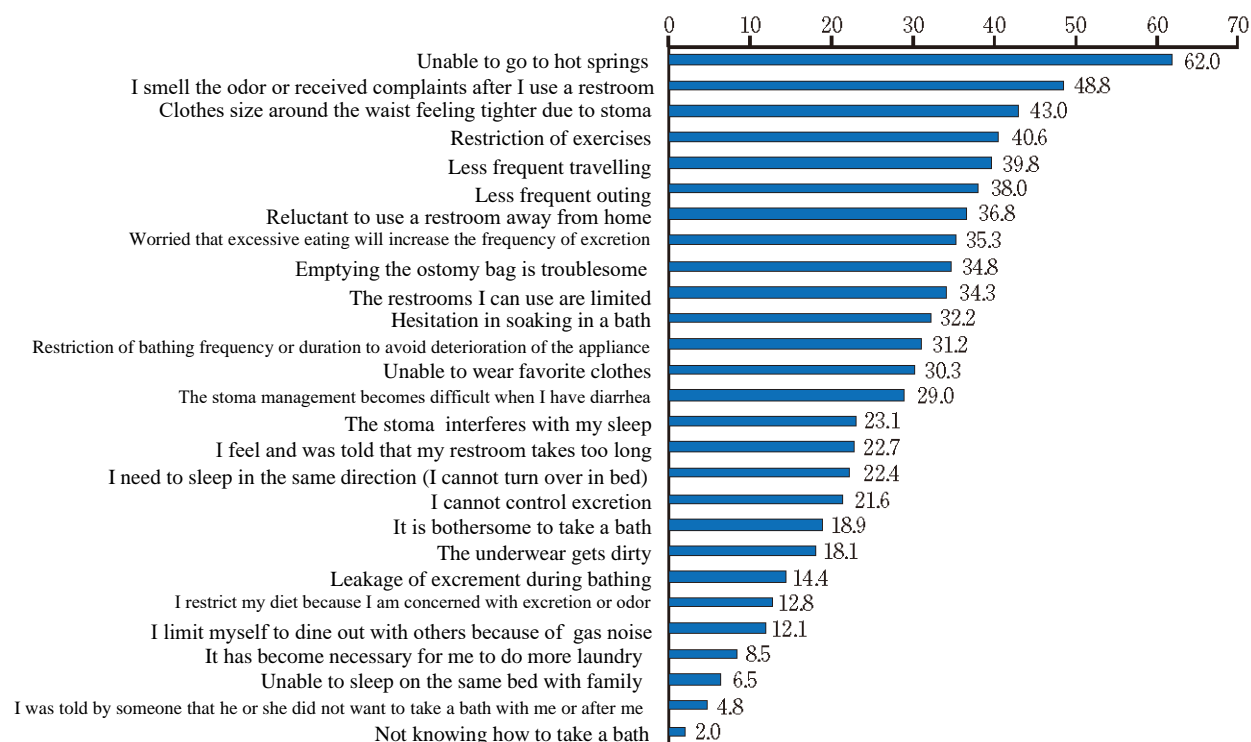
Difficulties experienced in daily life (multiple choices) Number of respondents = 1,086



1) Difficulties experienced in daily life classified by the types of stoma

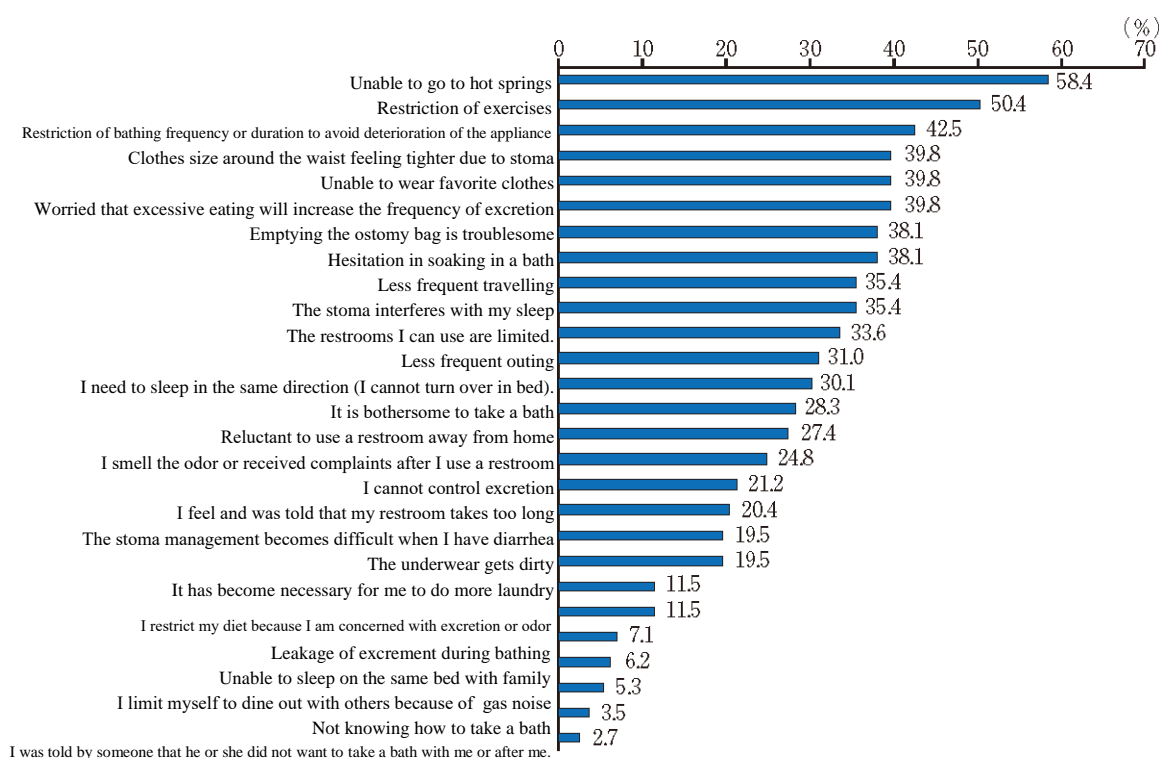
[1] Colostomy: Difficulties experienced in daily life (multiple choices) Number of respondents = 603

In the case of colostomy, the second most common trouble was “I smell the odor or received complaints after I use a restroom”



[2] Ileostomy: Difficulties experienced in daily life (multiple choices) Number of respondents = 113

In the case of ileostomy, the second most common trouble was “restriction of exercises.”



[3] Urostomy: Difficulties experienced in daily life (multiple choices) Number of respondents = 203

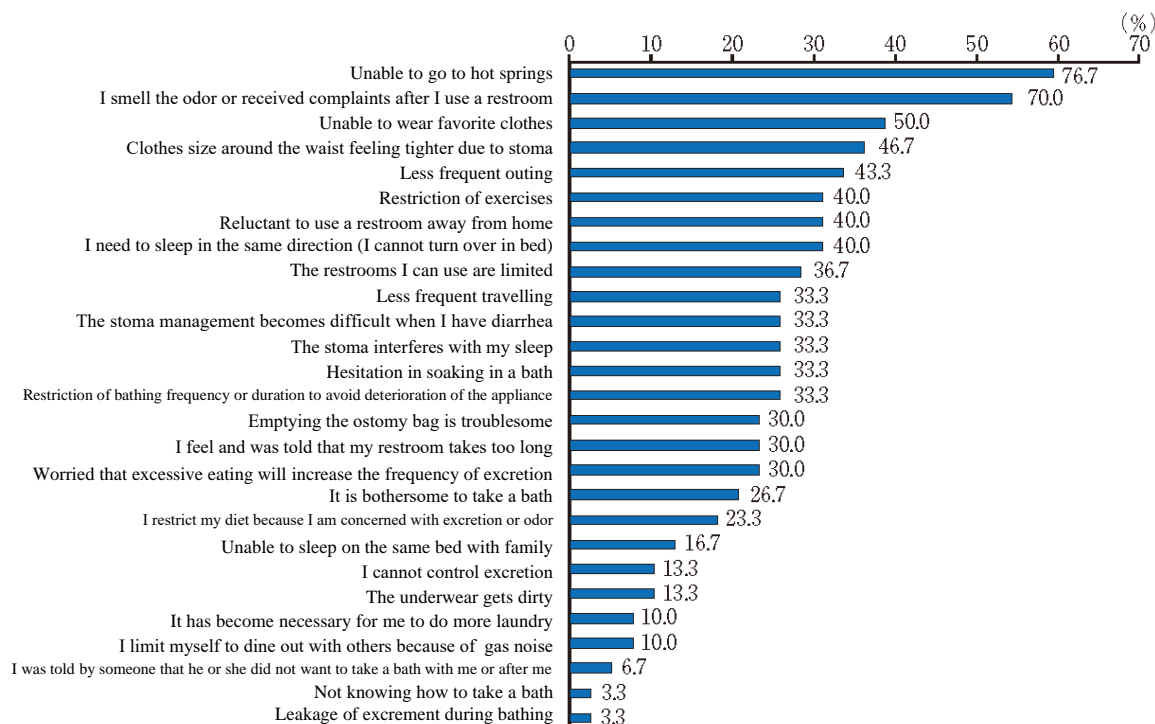
In the case of urostomy, the second most common trouble was “I need to sleep in the same direction (I cannot turn over in bed).”



[4] Double stoma: Difficulties experienced in daily life (multiple choices)

Number of respondents = 30

The second most common trouble was “I smell the odor or received complaints after I use a restroom”

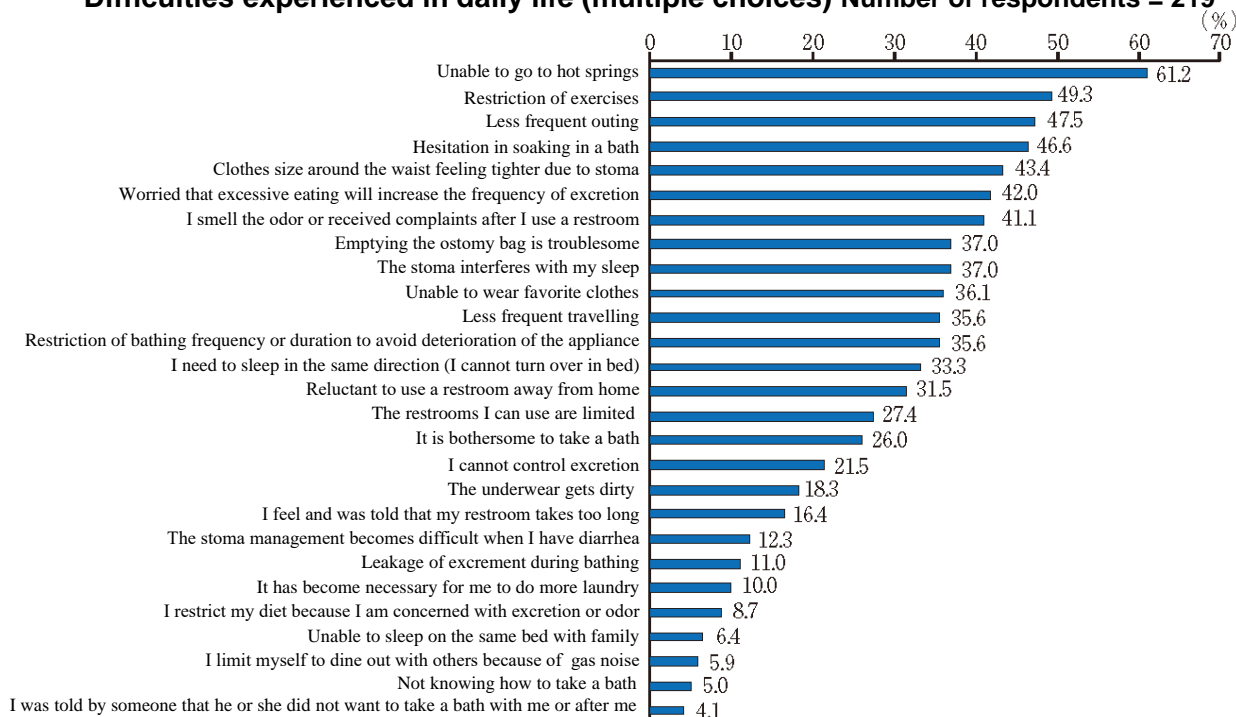


2) Difficulties experienced in daily life classified by the duration of stoma

The most common trouble was “Unable to go to hot springs” regardless of the duration.

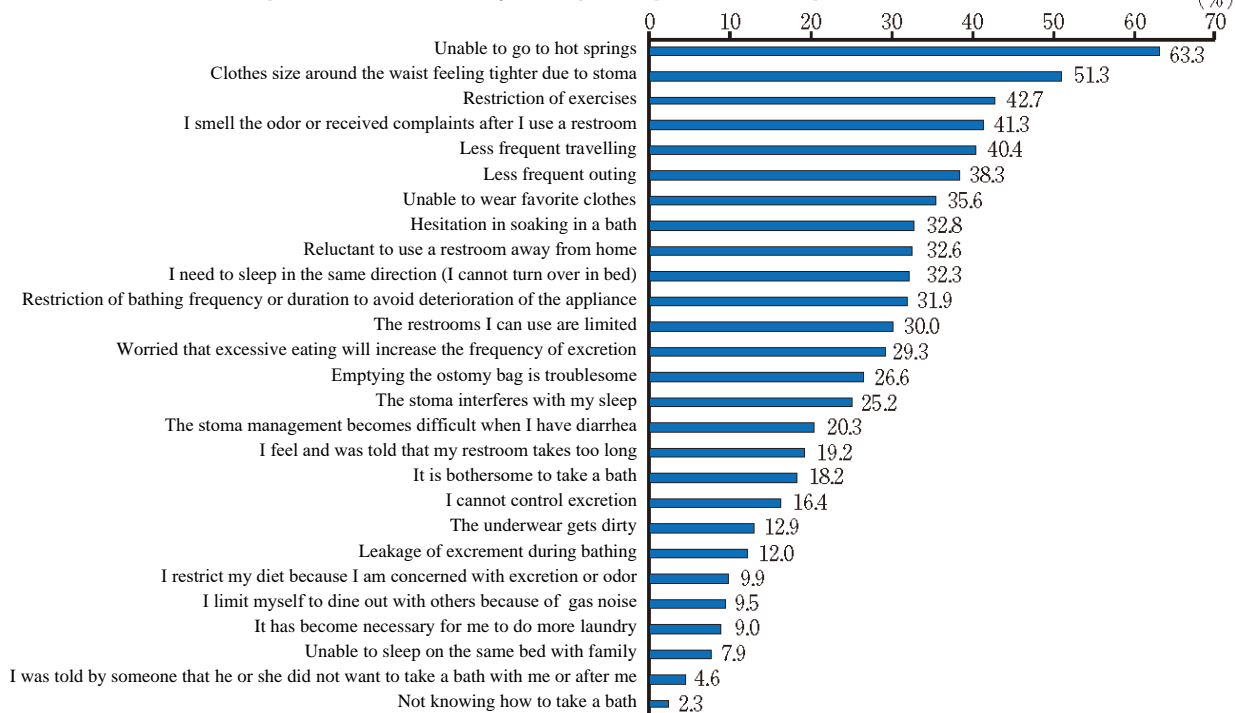
[1] Less than 1 year

Difficulties experienced in daily life (multiple choices) Number of respondents = 219



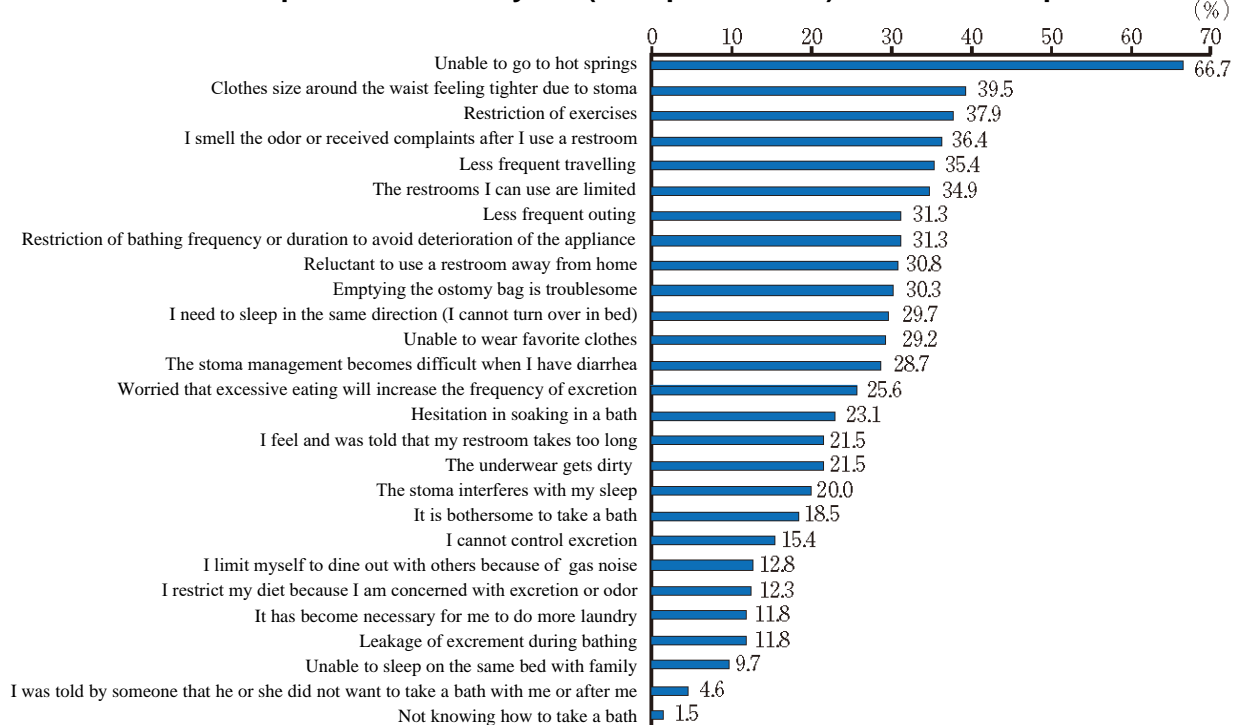
[2] 1 to 5 years

Difficulties experienced in daily life (multiple choices) Number of respondents = 432 (%)



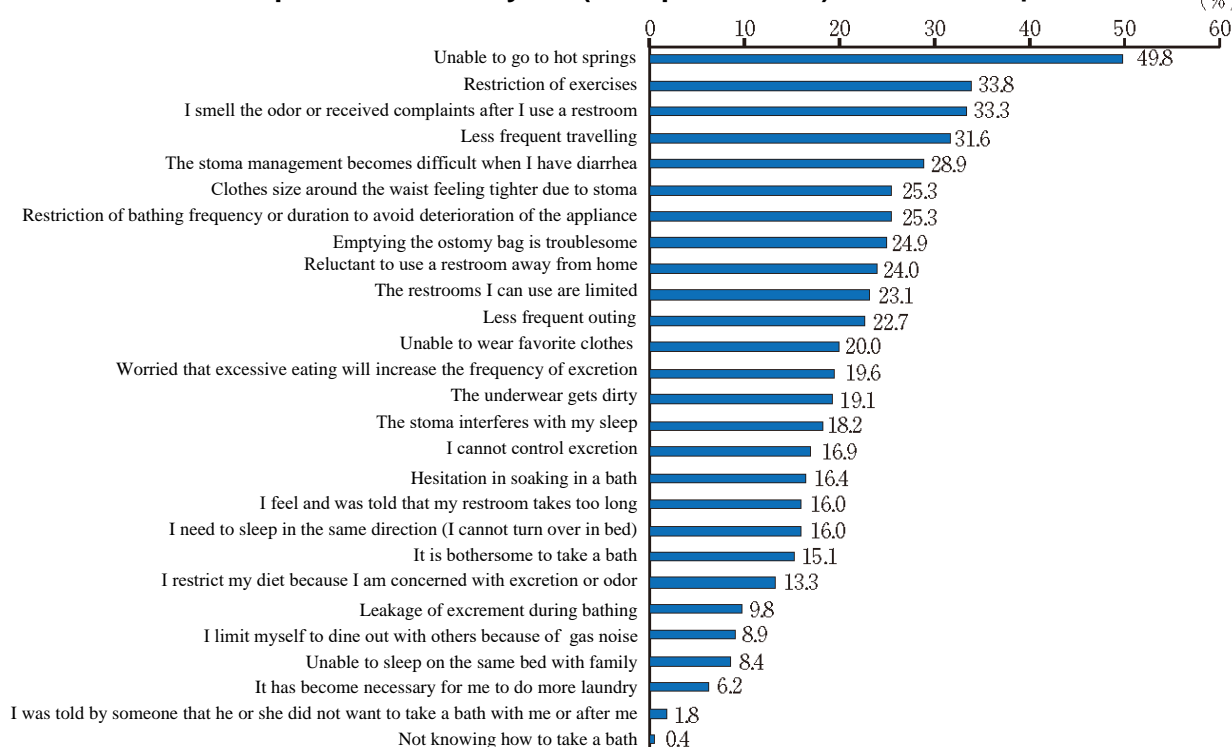
[3] 6 to 10 years

Difficulties experienced in daily life (multiple choices) Number of respondents = 195 (%)



[4] 11 years or longer

Difficulties experienced in daily life (multiple choices) Number of respondents =225 (%)



3) Difficulties experienced in daily life with permanent or temporary stoma

“Unable to go to hot springs” was the most common trouble for both permanent and temporary stoma.

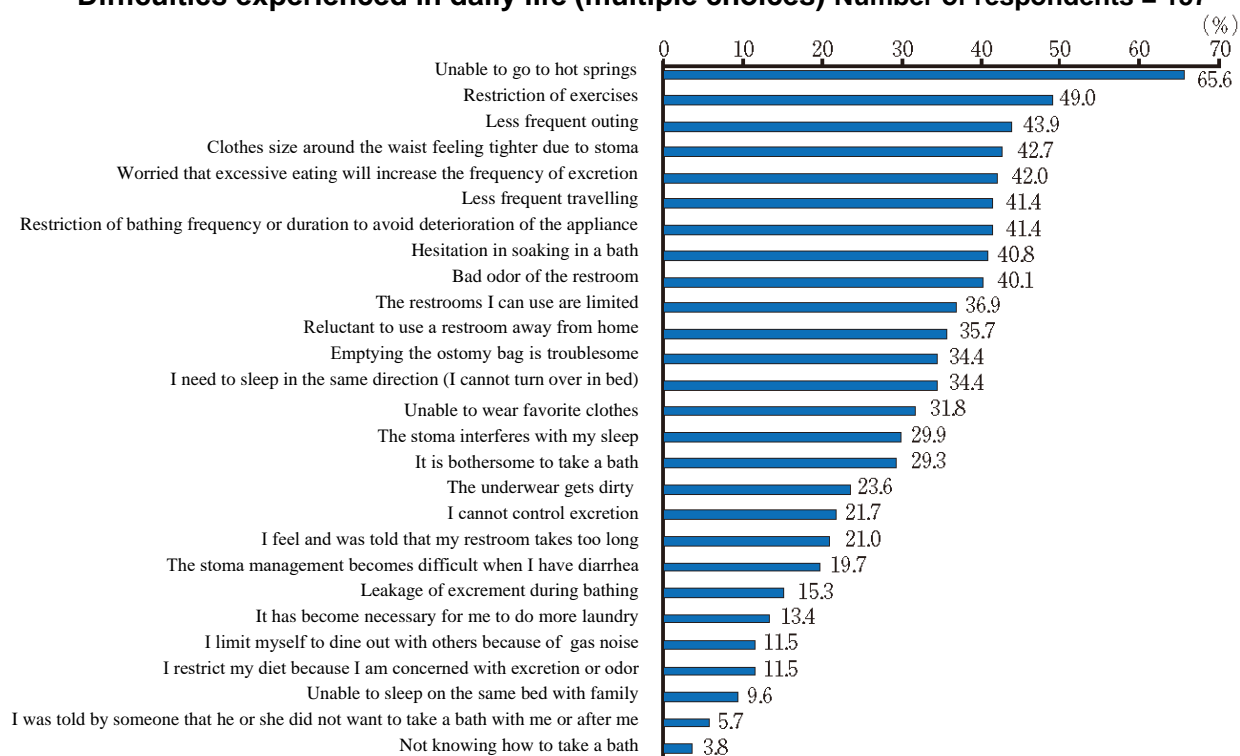
[11] Permanent stoma

Difficulties experienced in daily life (multiple choices) Number of respondents = 753 (%)



[2] Temporary stoma

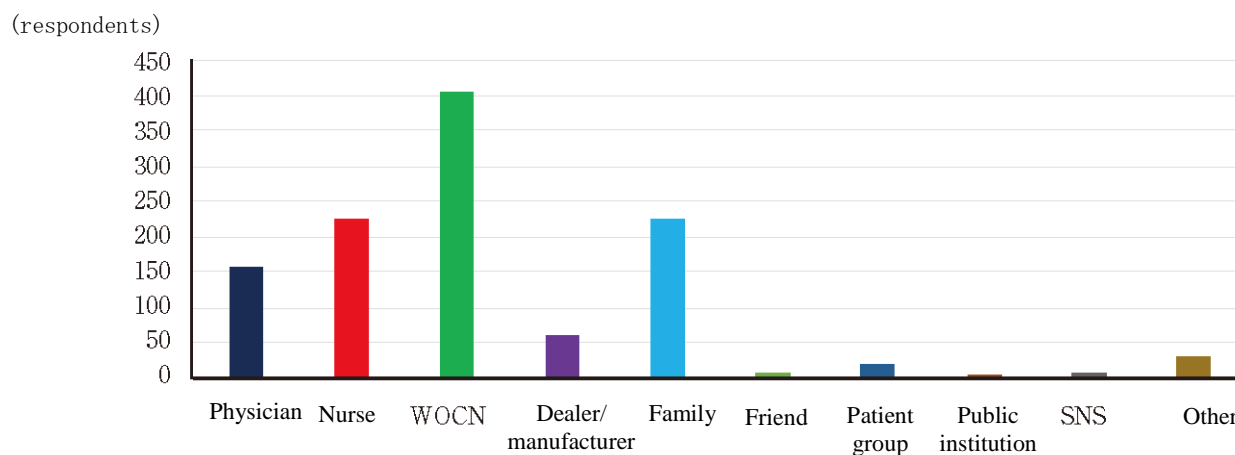
Difficulties experienced in daily life (multiple choices) Number of respondents = 157



4) Contacts for consultation made when having difficulties in daily life

First priority contact made for consultation in daily life

Number of respondents = 946

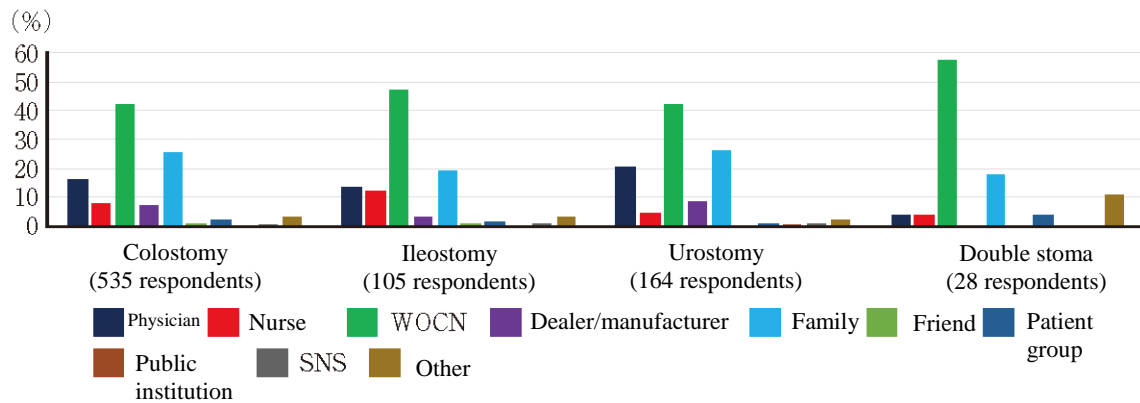


[1] Results by types of stoma (daily life)

In each category, the WOC was the most preferred contact for consultation.

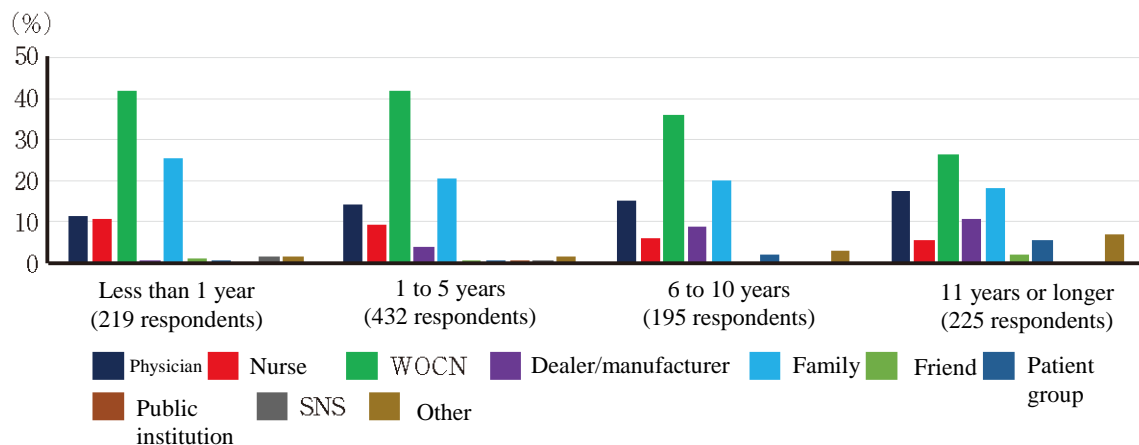
In many cases, family members are also consulted.

First priority contact made for consultation in daily life



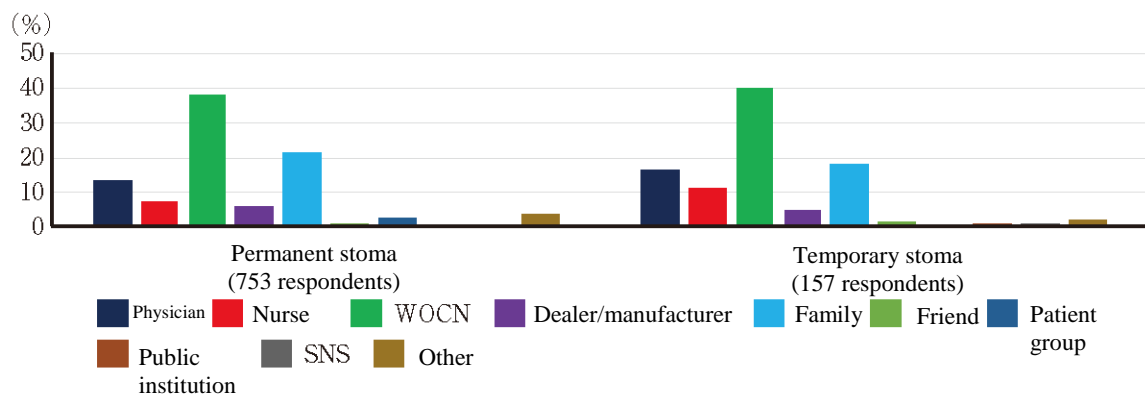
[2] Results by duration of stoma (daily life)

First priority contact made for consultation in daily life



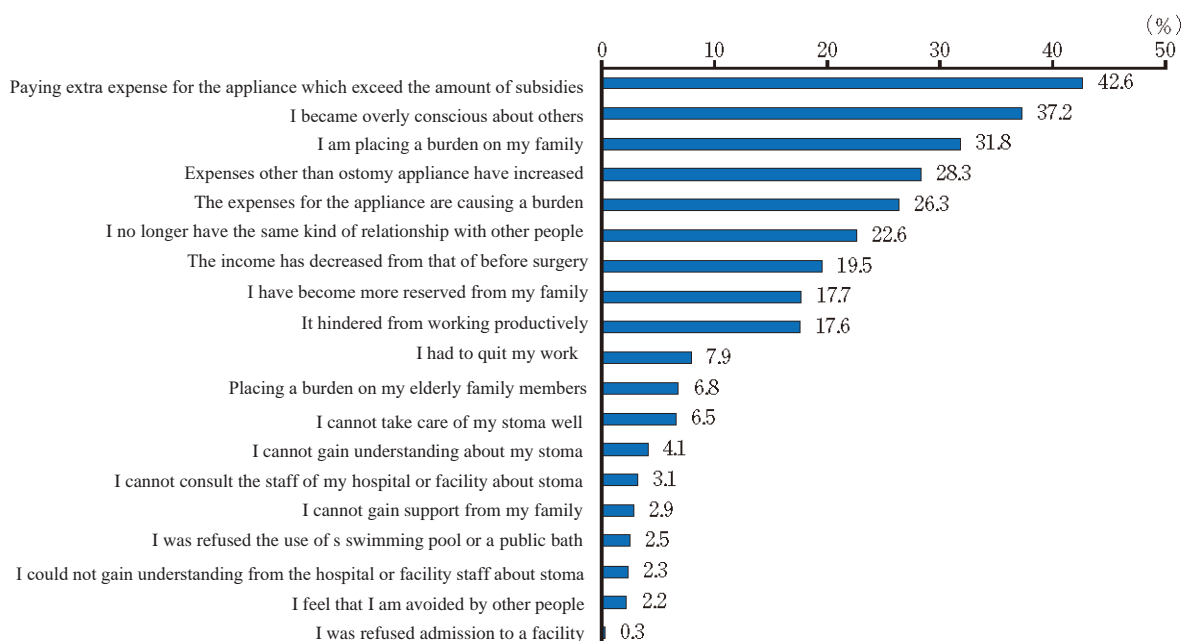
[3] Results by permanent or temporary stoma (daily life)

First priority contact made for consultation in daily life



3. Difficulties Experienced in Social Life

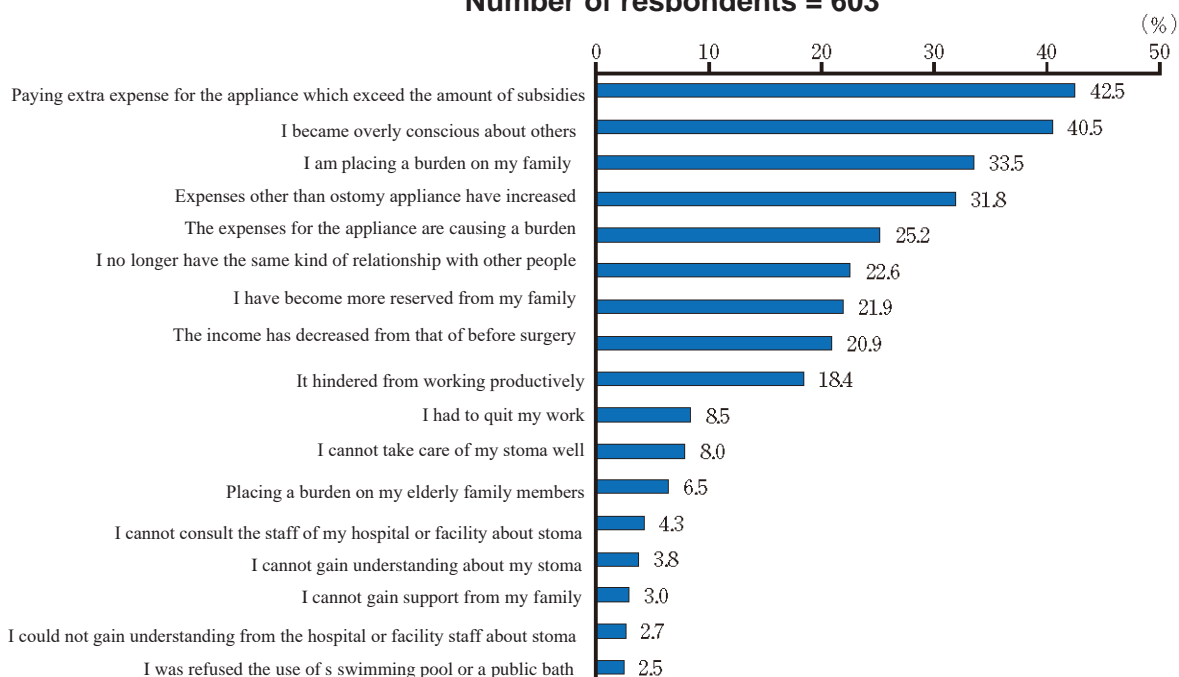
Difficulties experienced in social life (multiple choices) Number of respondents = 1,086



1) Difficulties experienced in social life classified by the types of stoma

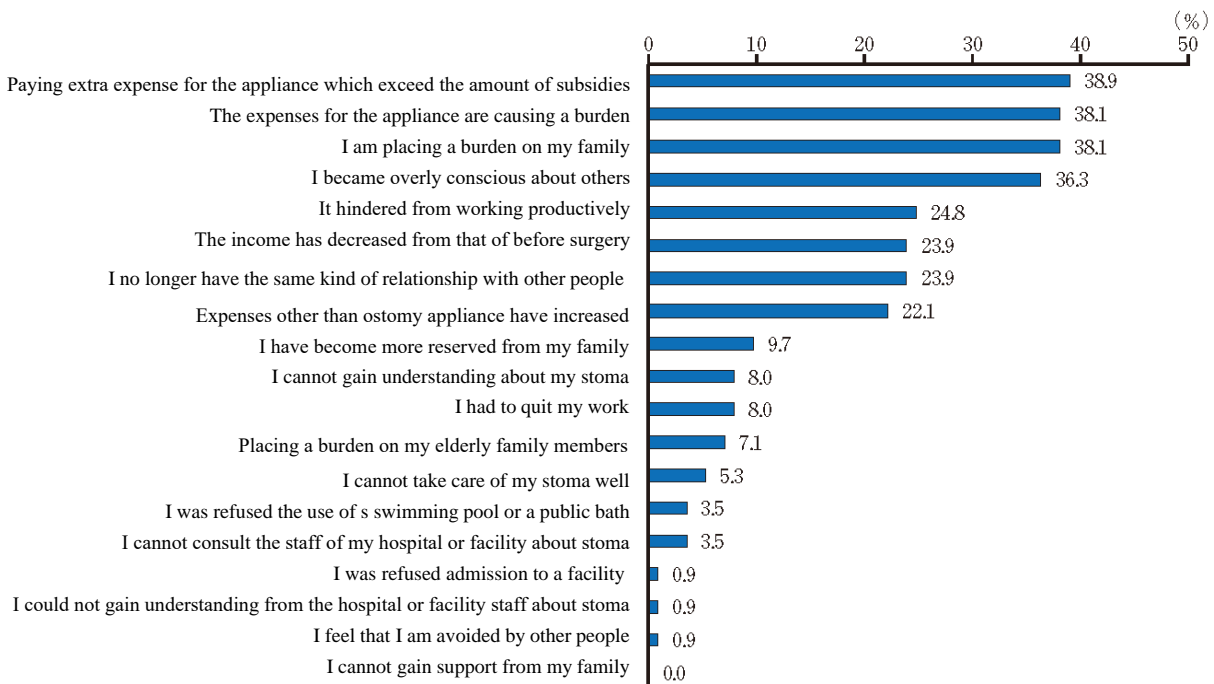
The most common trouble experienced in social life was “Paying expenses for appliance, which exceed the amount of subsidies” for all stomas. “The expenses for the appliance are causing a burden,” “I have come to be concerned about other people,” and “I am placing a burden on my family” are also ranked high for all stomas.

[1] Colostomy: Difficulties experienced in social life (multiple choices) Number of respondents = 603



[2] Ileostomy: Difficulties experienced in social life (multiple choices)

Number of respondents = 113



[3] Urostomy: Difficulties experienced in social life (multiple choices)

Number of respondents = 203



[4] Double stoma: Difficulties experienced in social life (multiple choices)

Number of respondents = 30

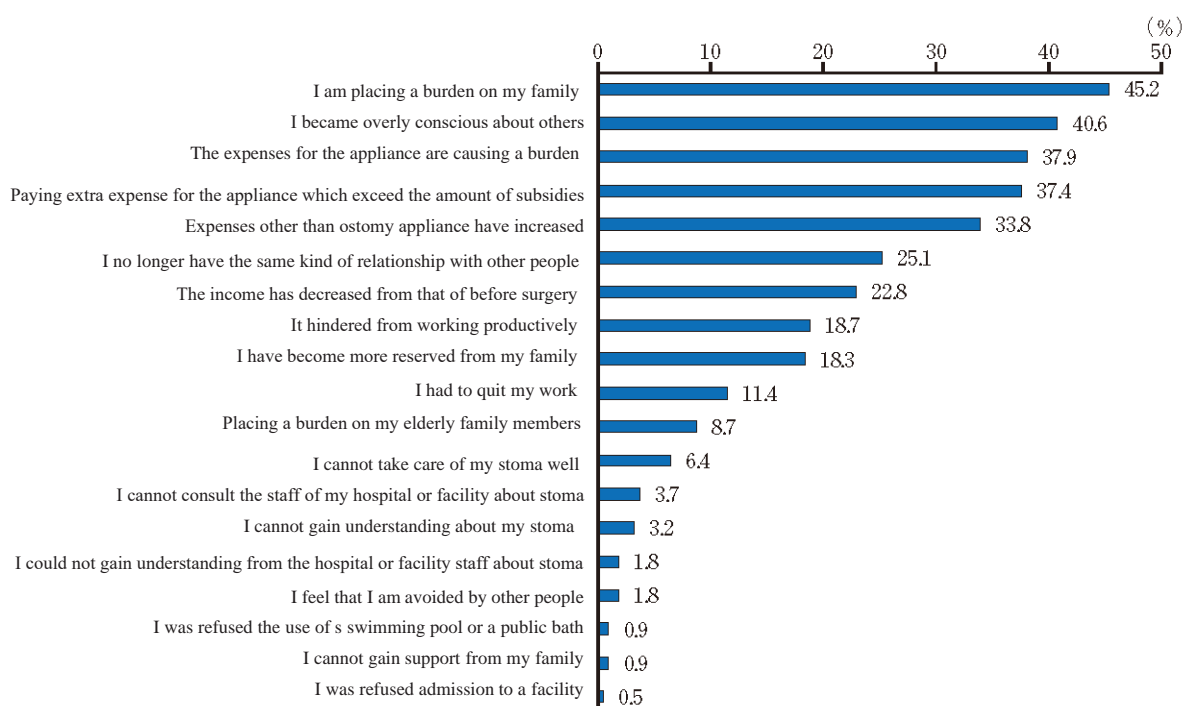


2) Difficulties experienced in social life classified by the duration of stoma

The most common trouble was “I am placing a burden on my family” (45%) in the respondents holding the stoma for less than 1 year, while “Paying expenses for appliance, which exceed the amount of subsidies” was the most common trouble among the respondents holding the stoma for 1 to 5 years, 6 to 10 years, and 11 years or longer.

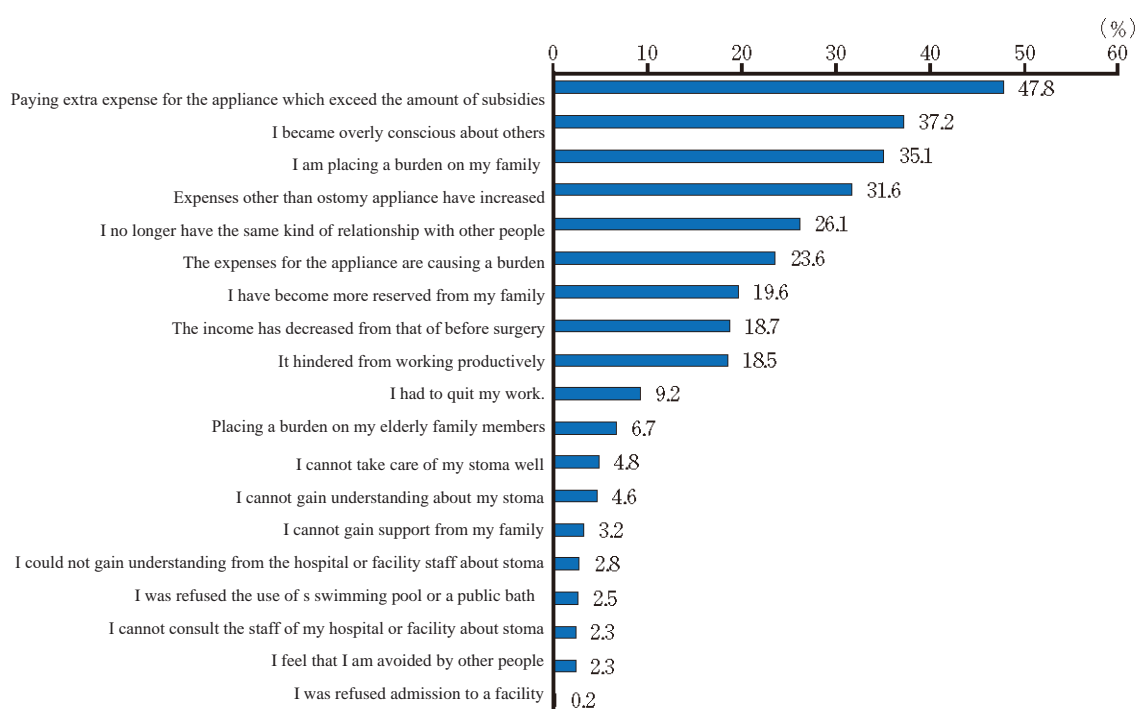
[1] Less than 1 year: Difficulties experienced in social life (multiple choices)

Number of respondents = 219



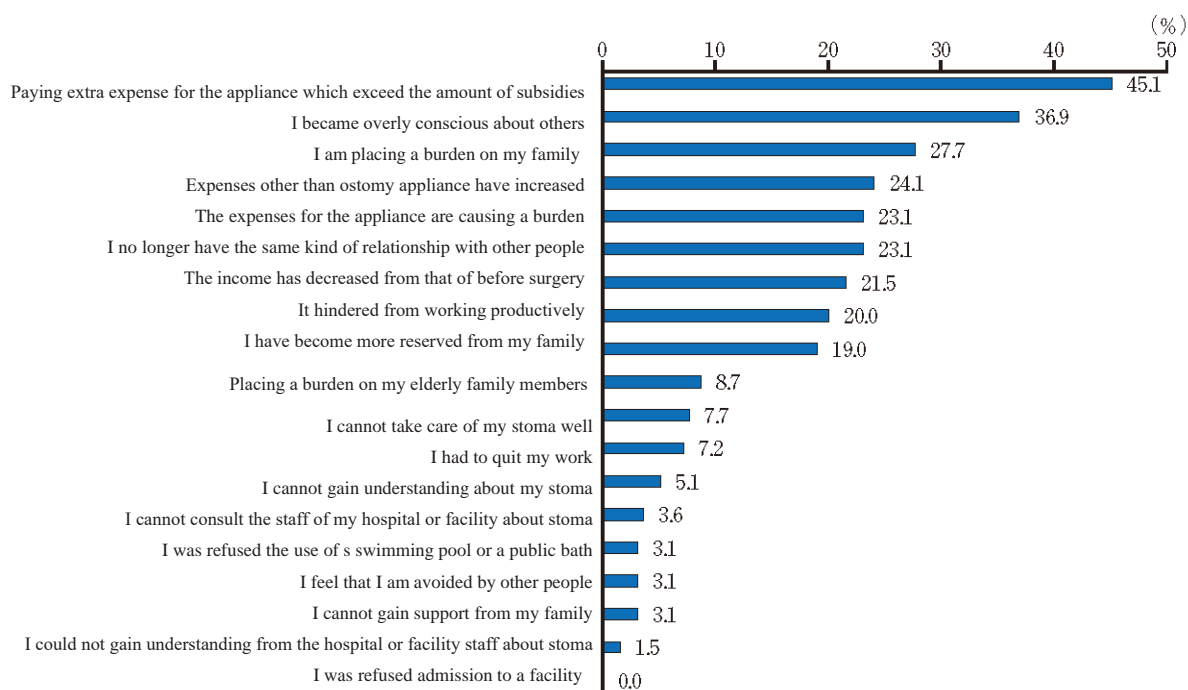
[2] 1 to 5 years: Difficulties experienced in social life (multiple choices)

Number of respondents = 432



[3] 6 to 10 years: Difficulties experienced in social life (multiple choices)

Number of respondents = 195

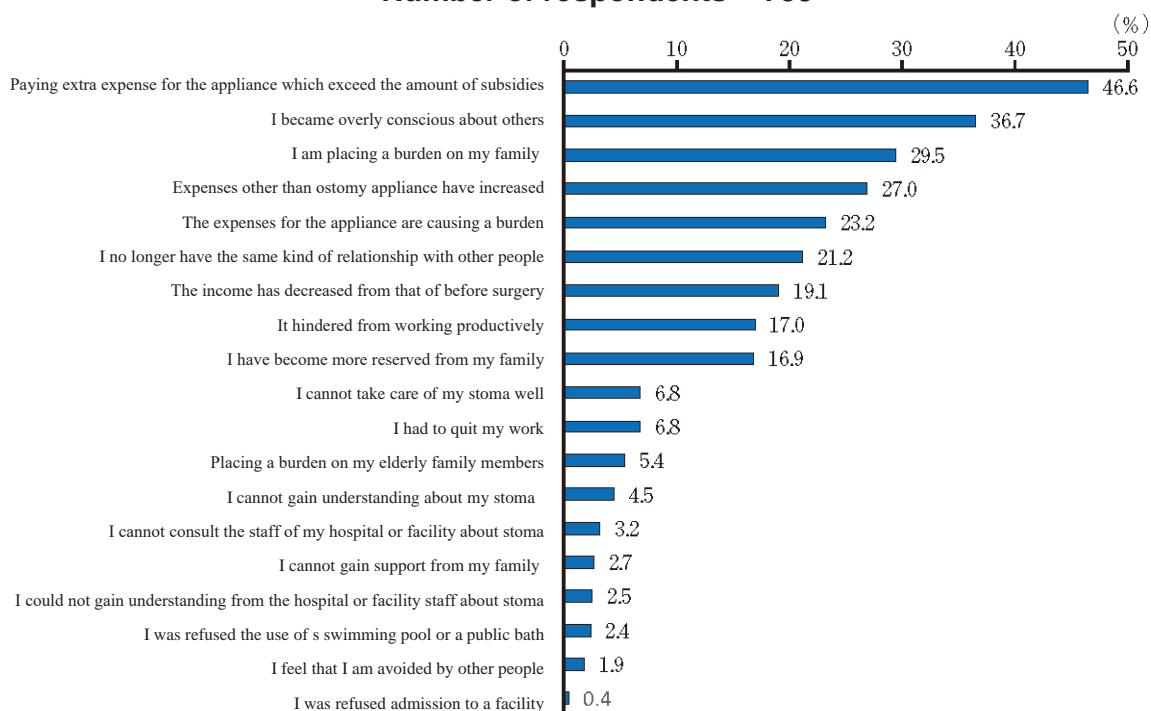


[4] 11 years or longer: Difficulties experienced in social life (multiple choices)
Number of respondents = 225

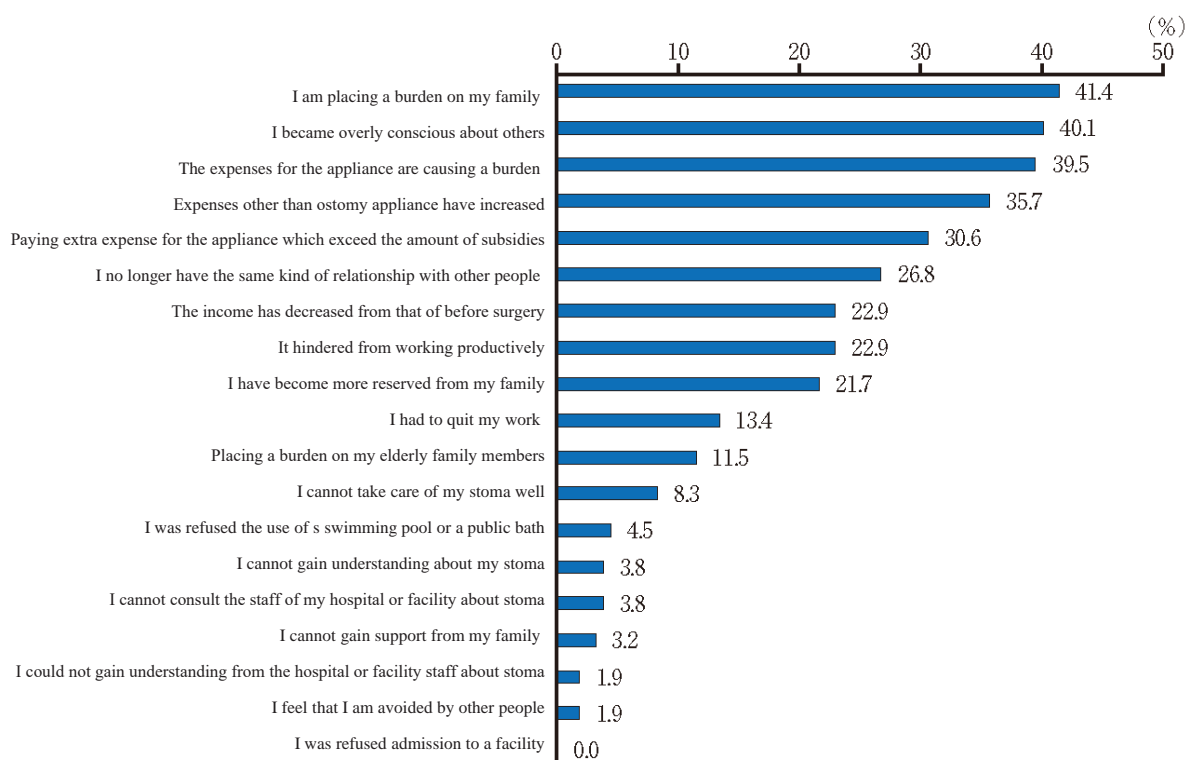


3) Difficulties experienced in social life with permanent or temporary stoma
The most common trouble was “Paying expenses for the appliance, which exceed the amount of subsidies” (46%) for the permanent stoma, and “I am placing a burden on my family” (41%) for the temporary stoma.

[1] Permanent stoma: Difficulties experienced in social life (multiple choices)
Number of respondents = 753



[2] Temporary stoma: Difficulties experienced in social life (multiple choices)
Number of respondents = 157

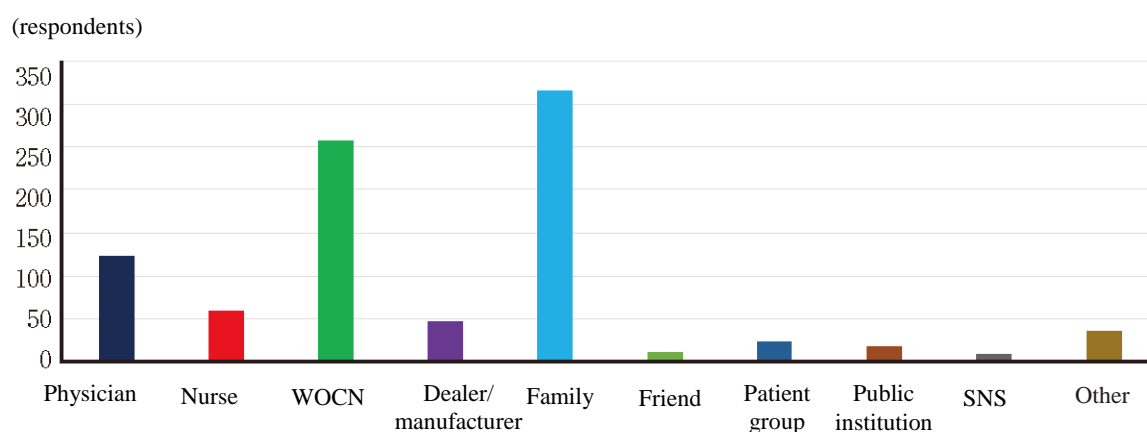


4) Contacts for consultation made when having difficulties in social life

“Family” was ranked at the top for consultation in social life

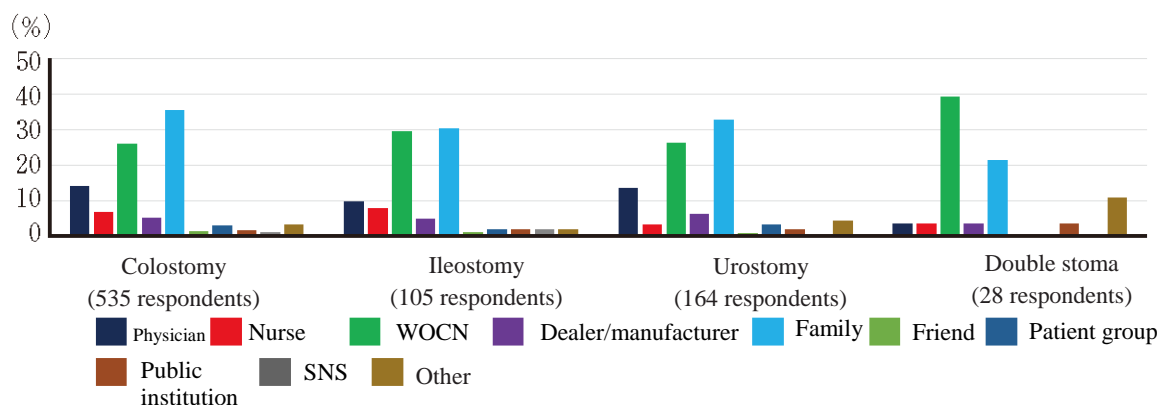
First priority contact made for consultation in social life

Number of respondents = 946



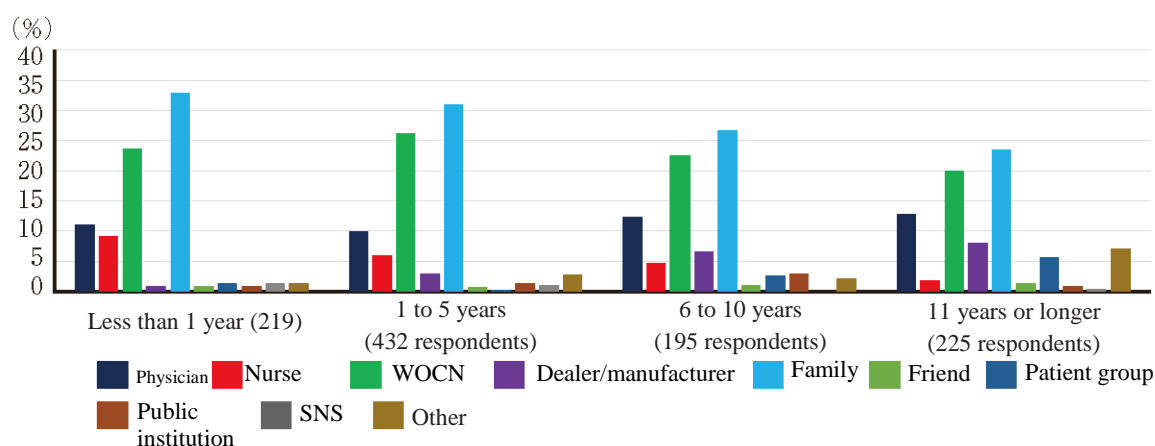
[1] Results by types of stoma (social life)

First priority contact made for consultation in social life



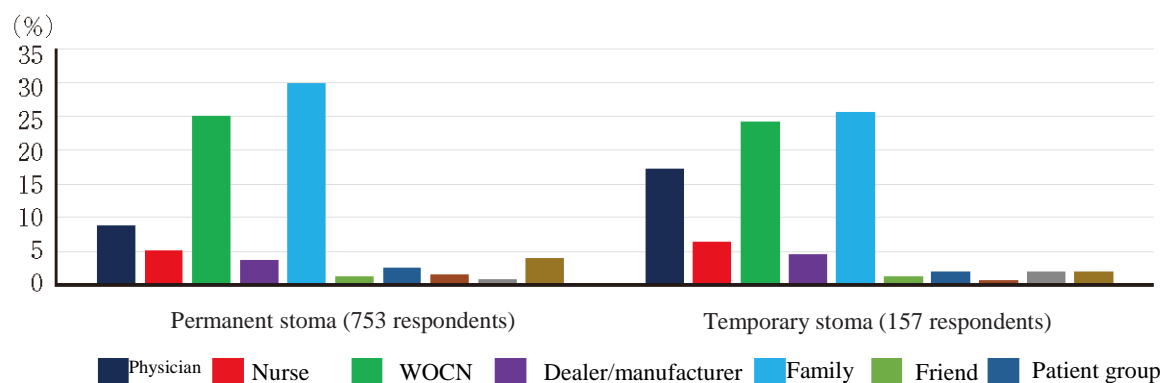
[2] Results by duration of stoma (social life)

First priority contact made for consultation in social life



[3] Results by permanent or temporary stoma (social life)

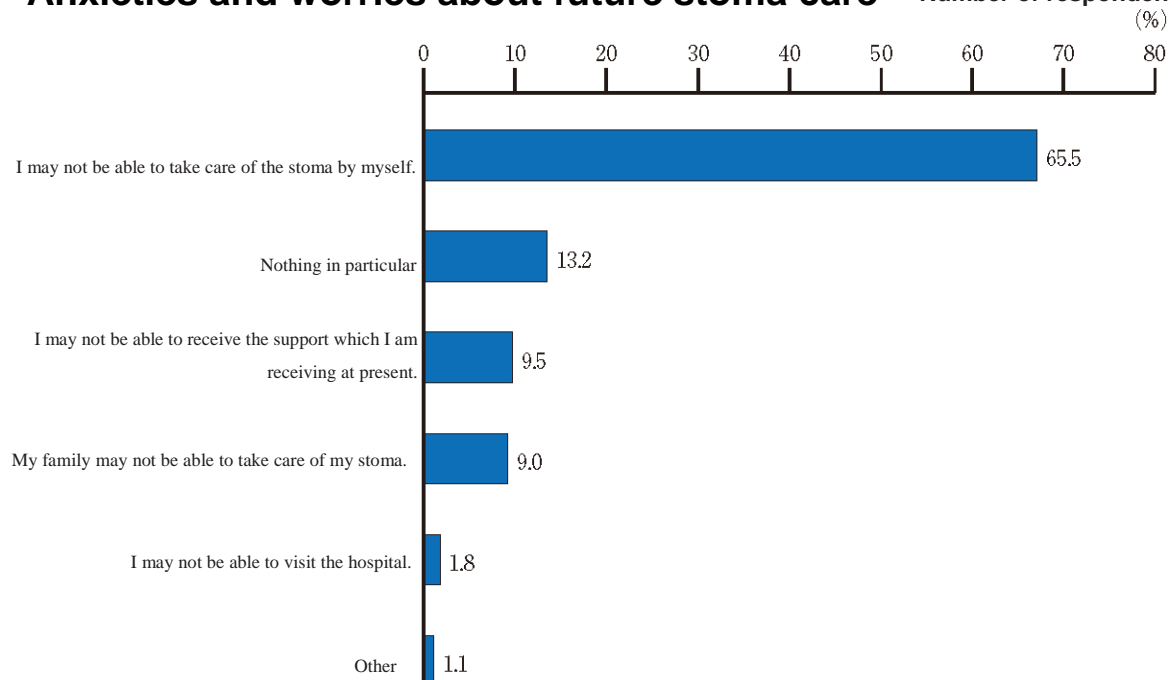
First priority contact made for consultation in social life



4. Anxieties for the future

Anxieties and worries about future stoma care

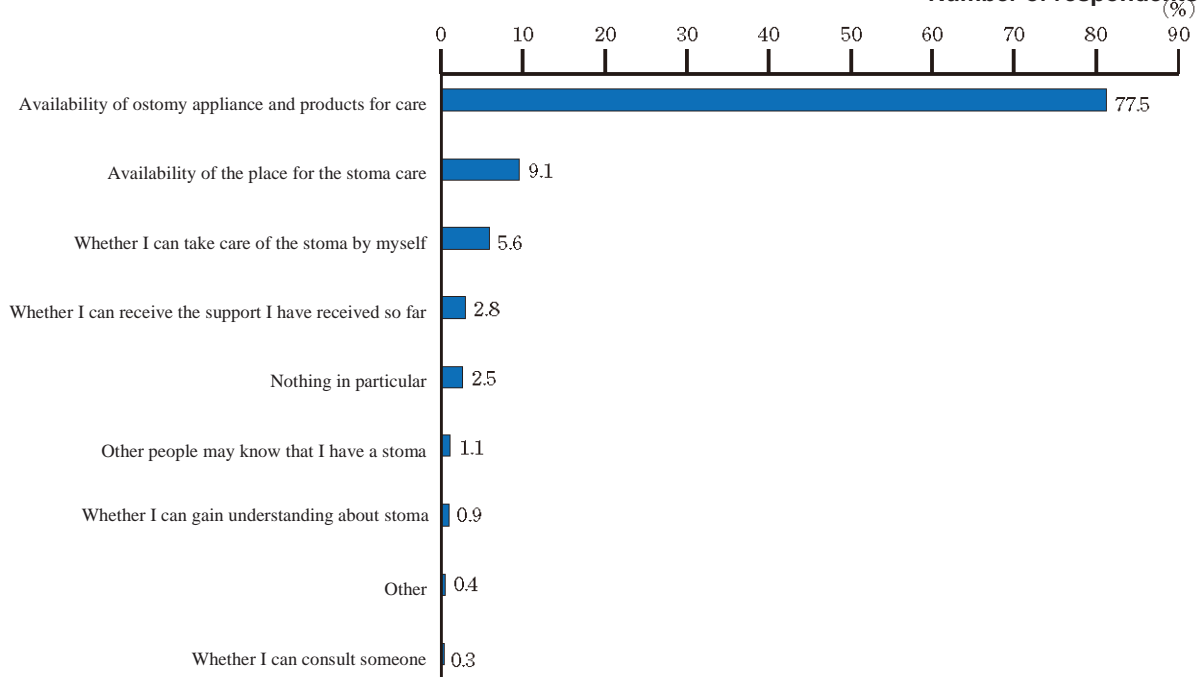
Number of respondents = 1,024



The most common anxiety or worry about the future stoma care was “I may not be able to take care of the stoma by myself” (66%).

Anxieties and worries about the time of disasters

Number of respondents = 1,045



The most common anxiety or worry about the time of disaster was “Availability of ostomy appliance and products for care” (78%).

5. Current stoma management

1) Monthly self-paid expenses for ostomy appliance/products for care (amount excluding public assistance)

Self-paid expenses for ostomy appliance/products for care

Number of respondents = 1,048

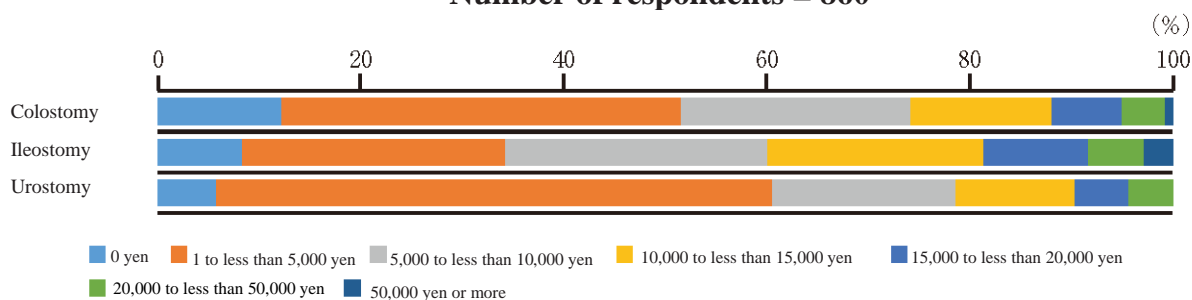
	Actual number	(%)
1. 0 yen	111	10.6
2. 1 to less than 5,000 yen	421	40.2
3. 5,000 to less than 10,000 yen	233	22.2
4. 10,000 to less than 15,000 yen	152	14.5
5. 15,000 to less than 20,000 yen	76	7.3
6. 20,000 to less than 50,000 yen	46	4.4
7. 50,000 yen or more	9	0.9
Total	1,048	100.0

Approximately 90% of ostomates paid out of pocket when purchasing ostomy appliance and products for care.

The amount paid was 1 yen to less than 5,000 yen for the largest proportion of respondents.

Self-paid expenses for ostomy appliance/products for care classified by types of stoma

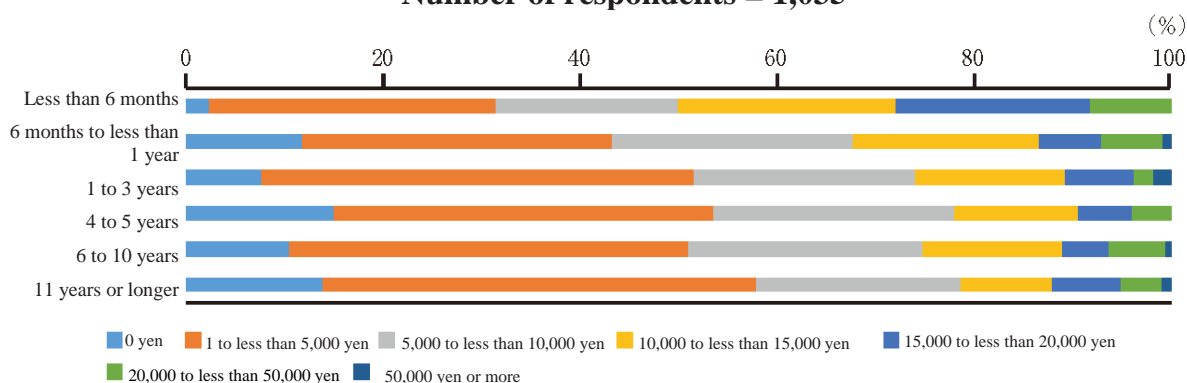
Number of respondents = 860



When classified by types of stoma, the proportion of the respondents paying 1 yen to less than 5,000 yen was the largest for colostomy and urostomy.

Self-paid expenses for ostomy appliance/products for care classified by the duration of stoma

Number of respondents = 1,035

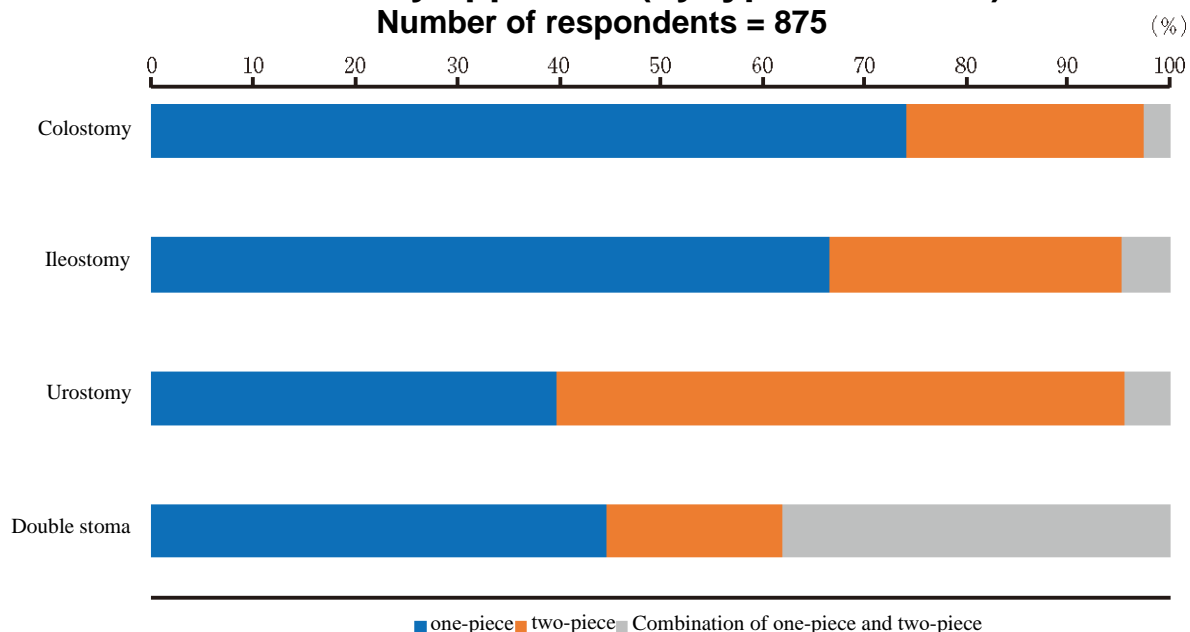


When classified by the duration of stoma, 97% of the respondents who had a stoma for less than 6 months paid the expenses out of pocket, and the amount was 5,000 yen or more for 69% of them.

6. Ostomy appliance

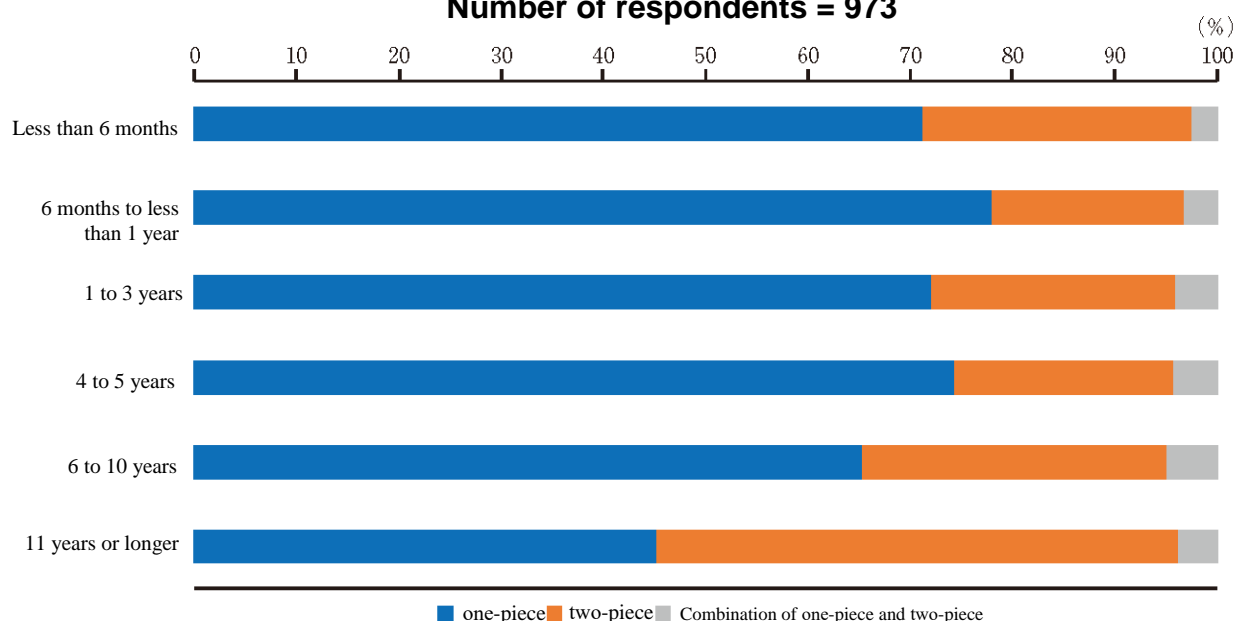
Kind of ostomy appliance (by types of stoma)

Number of respondents = 875



Kind of ostomy appliance (by the duration of stoma)

Number of respondents = 973



Current stoma management method

	Colostomy	Ileostomy	Gastrointestinal stoma (Details unknown)
1. Management with ostomy bag	508	104	39
2. Colostomy irrigation	6	0	0
3. Combination of ostomy bag with Colostomy irrigation	31	3	2
4. Other	4	0	0
Total	1,086	100.0	100.0

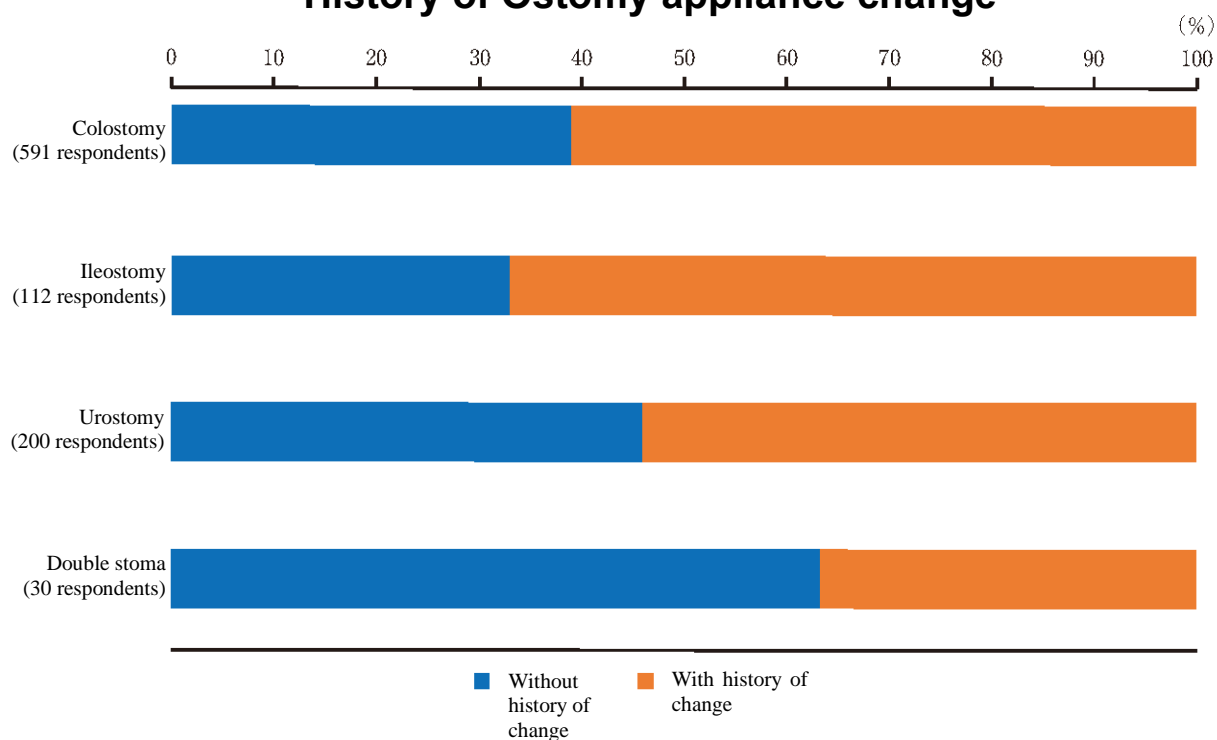
The percentage of the respondents who irrigate a stoma was 5%.

Have you ever changed your ostomy appliance to a different one?

	Actual number	(%)
1. Without history of change	436	41.0
2. With history of change	627	59.0
Total	1,086	100.0

More than half of the respondents have changed the type of the ostomy appliance.

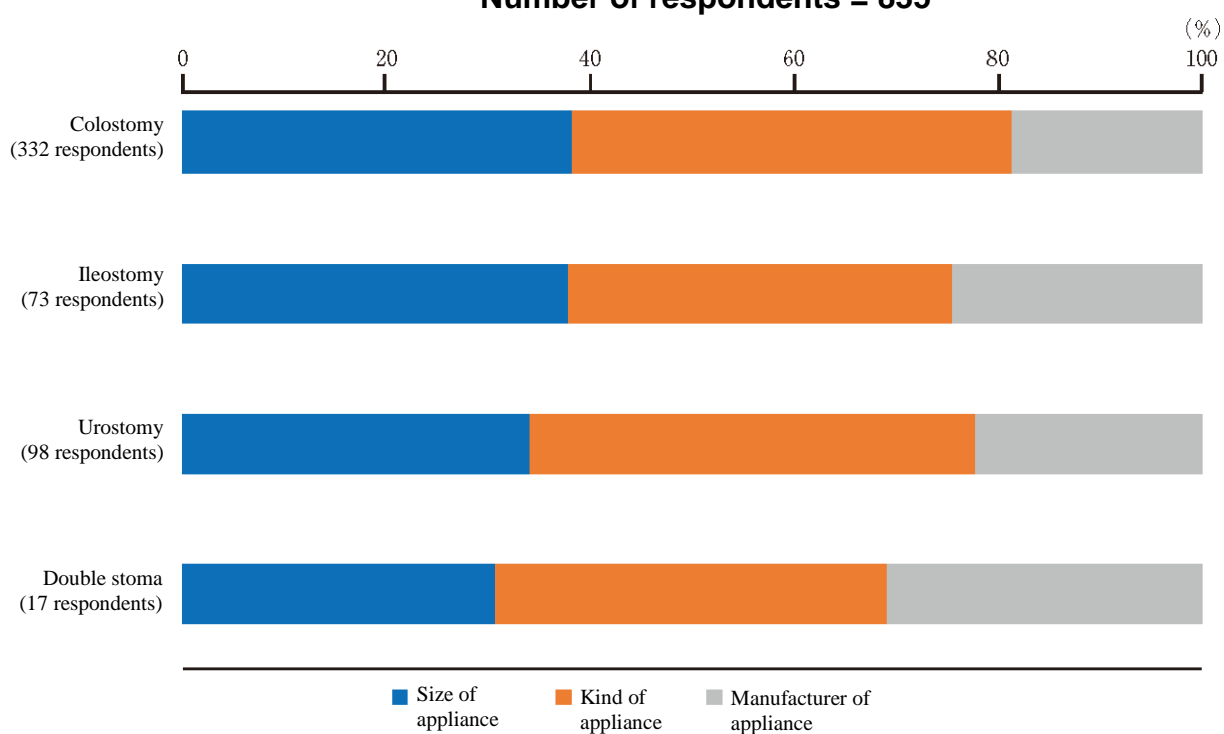
History of Ostomy appliance change



What was the change in the ostomy appliance? (multiple answers)

	Actual number	(%)
1. Size of appliance	346	37.4
2. Kind of appliance	392	42.4
3. Manufacturer of appliance	186	20.1
Total	924	20.1

Details of the change of ostomy appliance Number of respondents = 835

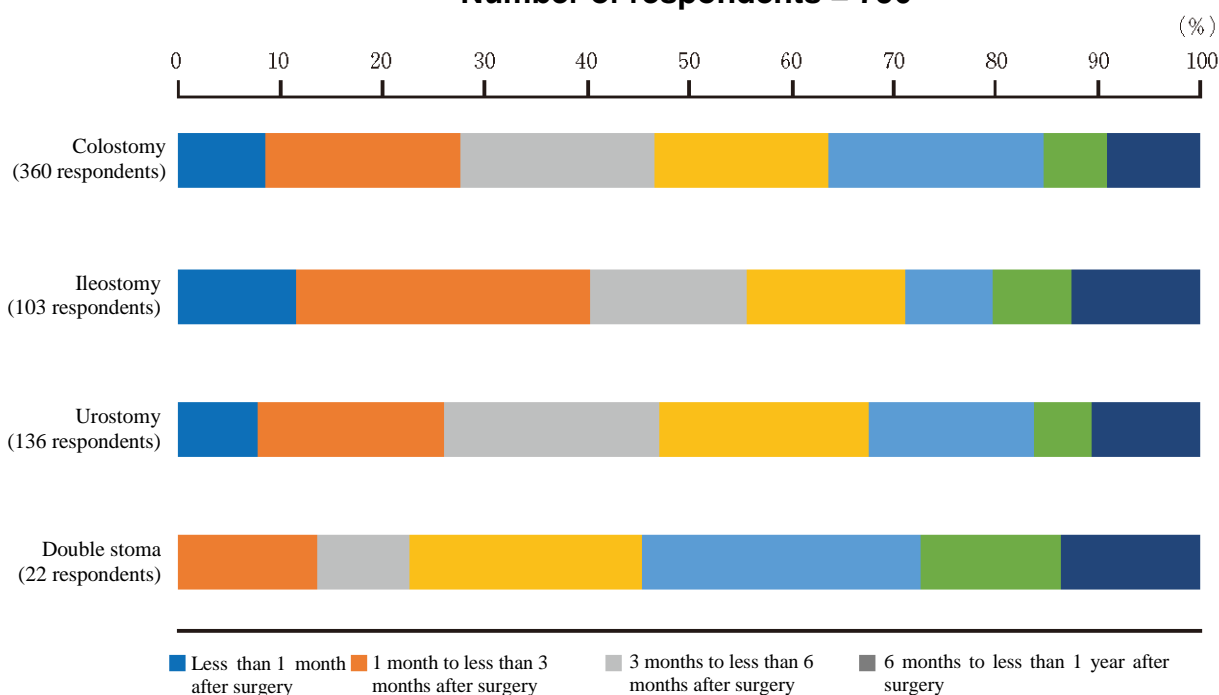


When was the ostomy appliance changed? (multiple answers)

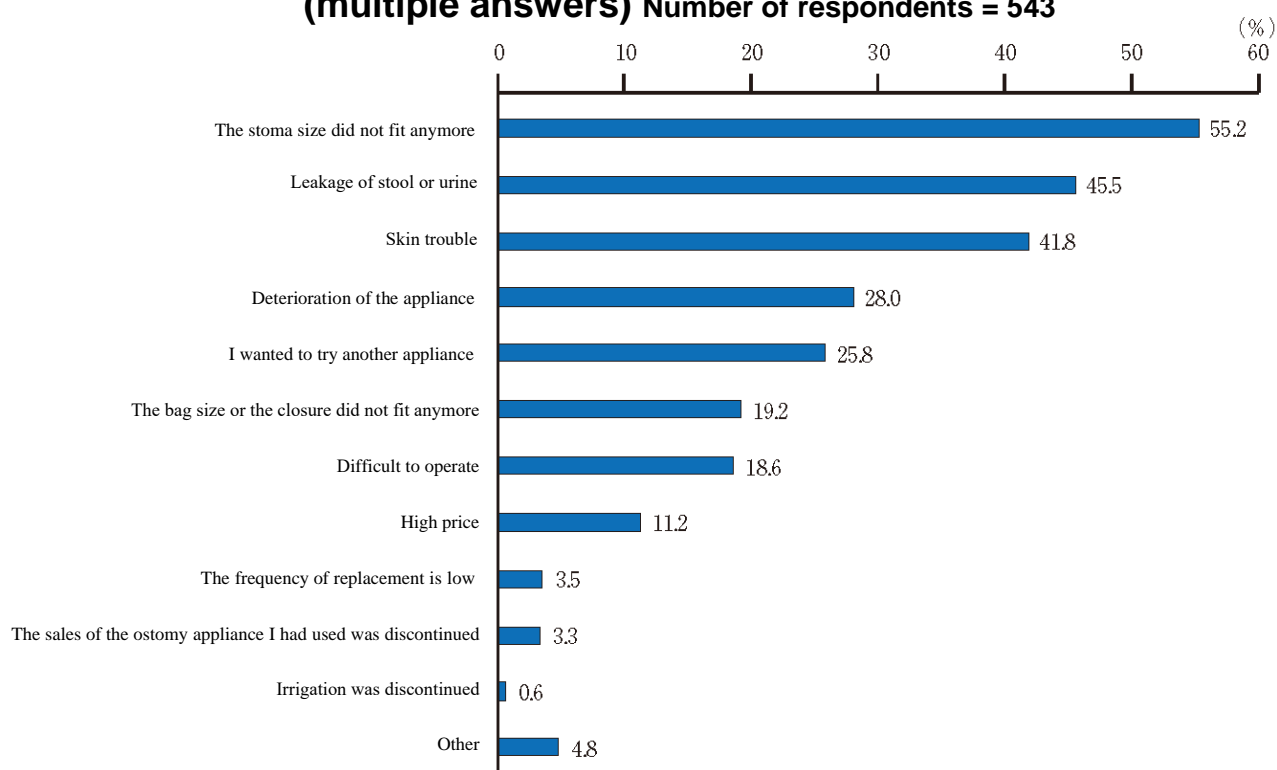
		Actual number	(%)
1.	Less than 1 month after surgery	71	8.4
2.	1 month to less than 3 months after surgery	171	20.3
3.	3 months to less than 6 months after surgery	161	19.1
4.	6 months to less than 1 year after surgery	149	17.7
5.	1 year to less than 3 years after surgery	155	18.4
6.	3 years to less than 5 years after surgery	55	6.5
7.	5 years or longer after surgery	81	9.6
Total		843	100.0

Timing of Ostomy appliance change (by types of stoma)

Number of respondents = 756

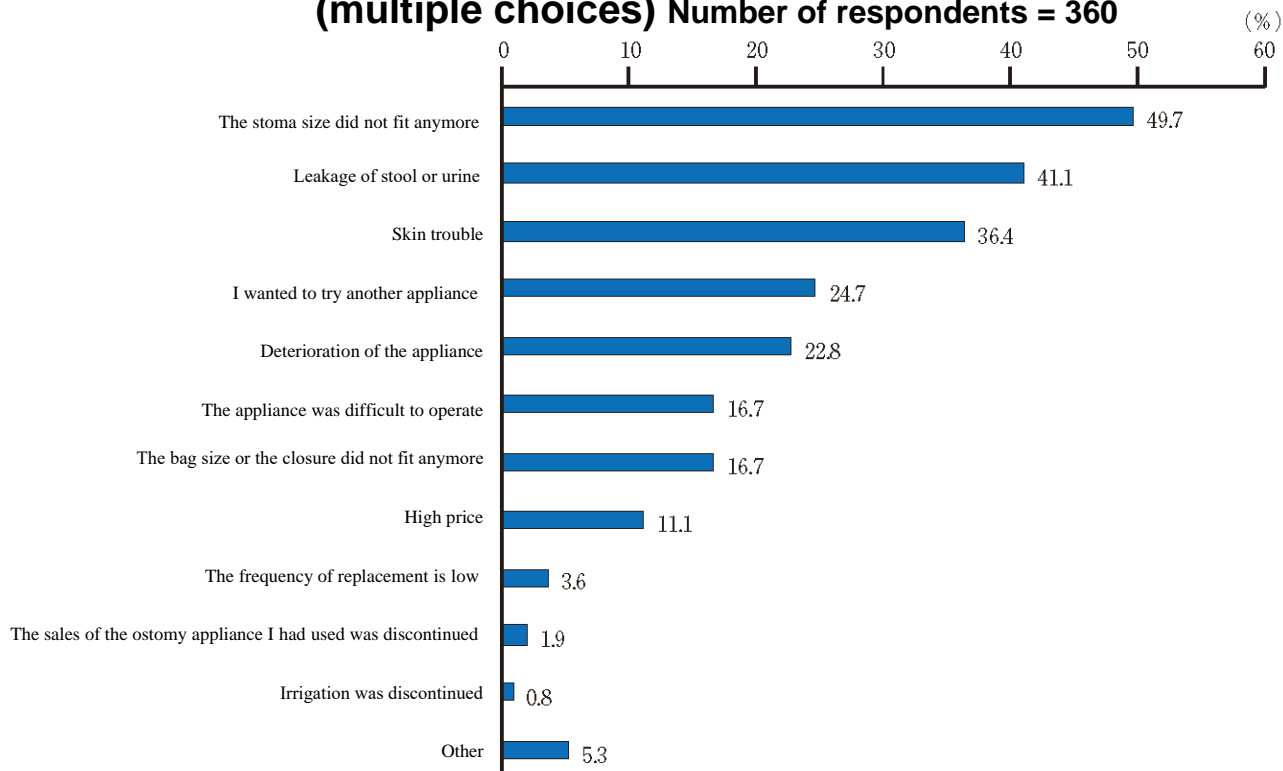


Overall: Reasons for change of the ostomy appliance (multiple answers) Number of respondents = 543



The most common reason for the change of the appliance was “The stoma size did not fit anymore,” followed by “Leakage of stool or urine,” “Skin irritation,” “The sales of the appliance I had used was discontinued,” and “I wanted to try another appliance.”

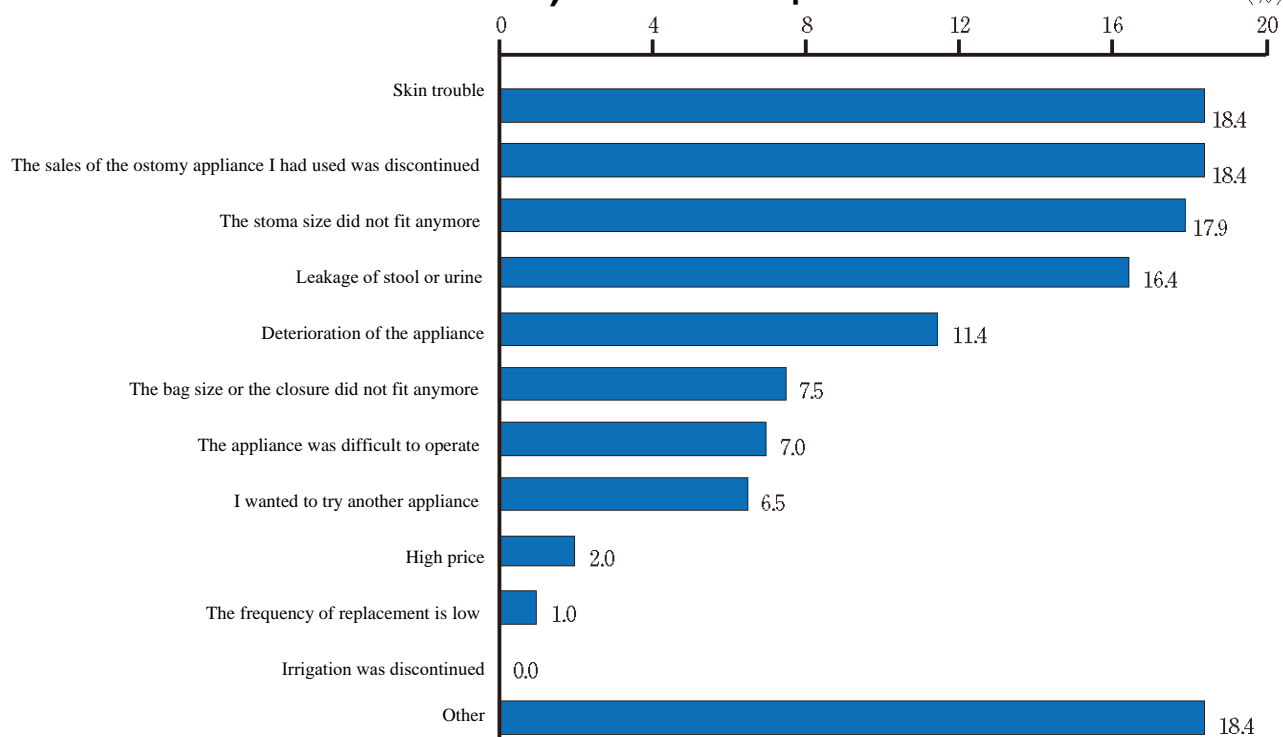
Colostomy: Details of the change of ostomy appliance (multiple choices) Number of respondents = 360



Ileostomy: Details of the change of ostomy appliance (multiple choices)

Number of respondents = 75

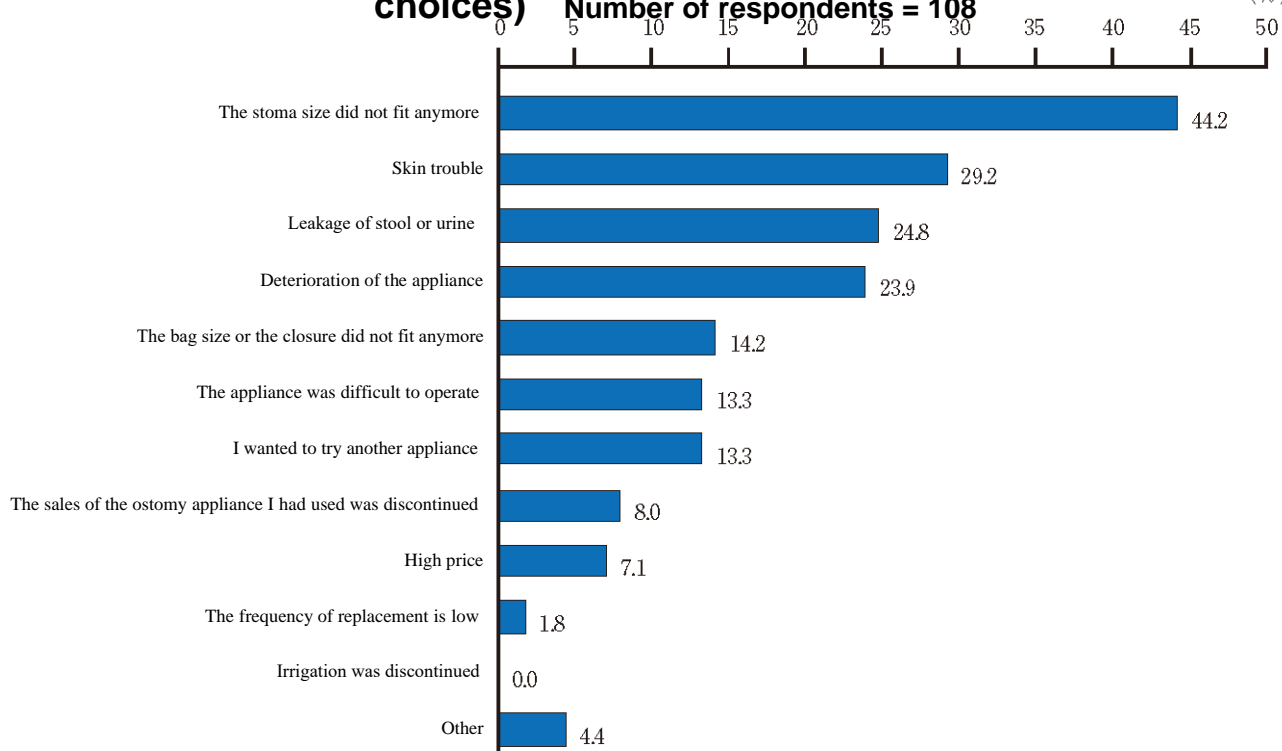
(%)



Urostomy: Details of the change of ostomy appliance (multiple choices)

Number of respondents = 108

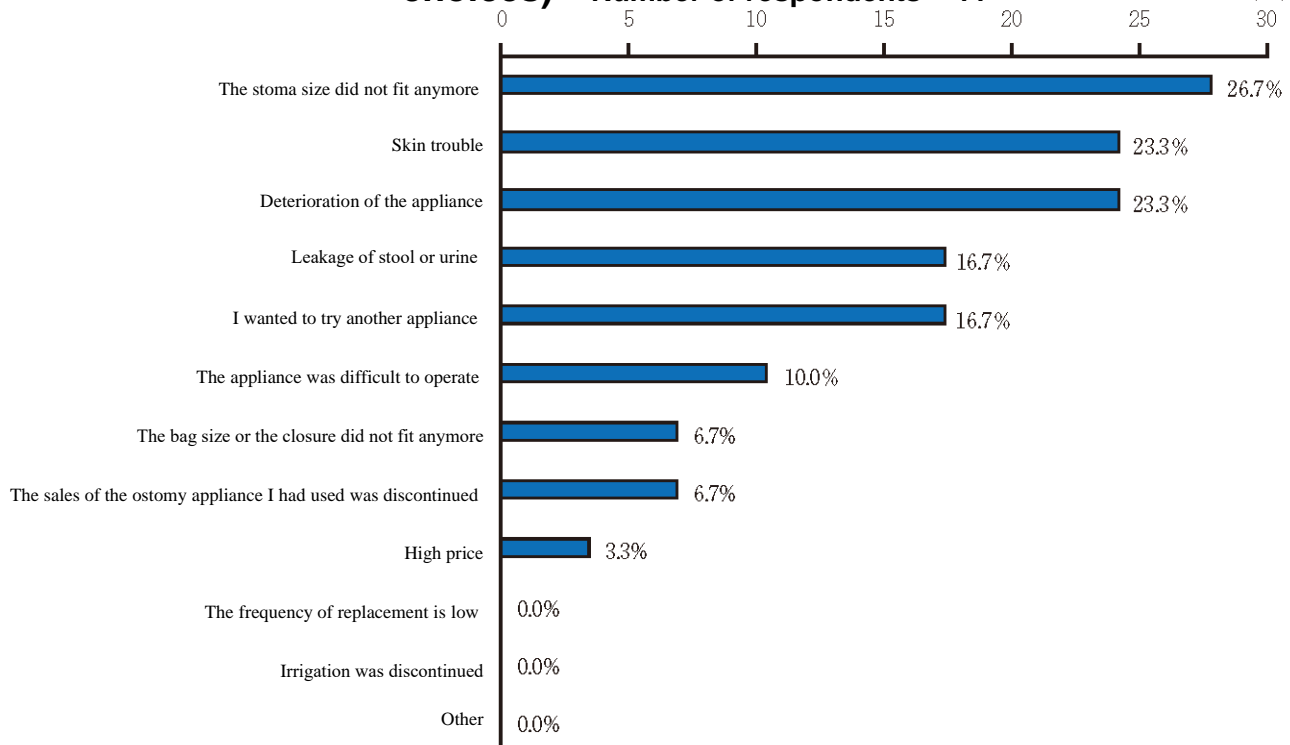
(%)



Double stoma: Details of the change of ostomy appliance (multiple choices)

Number of respondents = 11

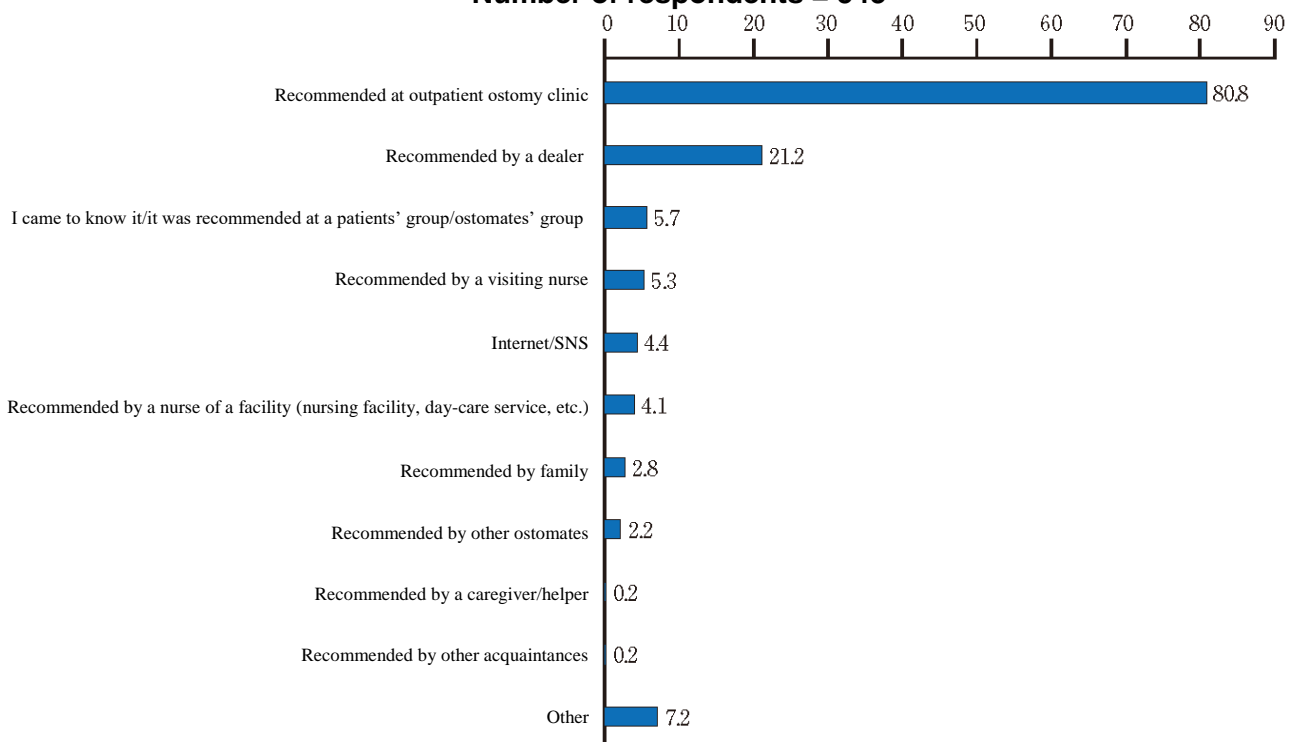
(%)



Where did you find out about the ostomy appliance that was changed?(multiple choices)

Number of respondents = 543

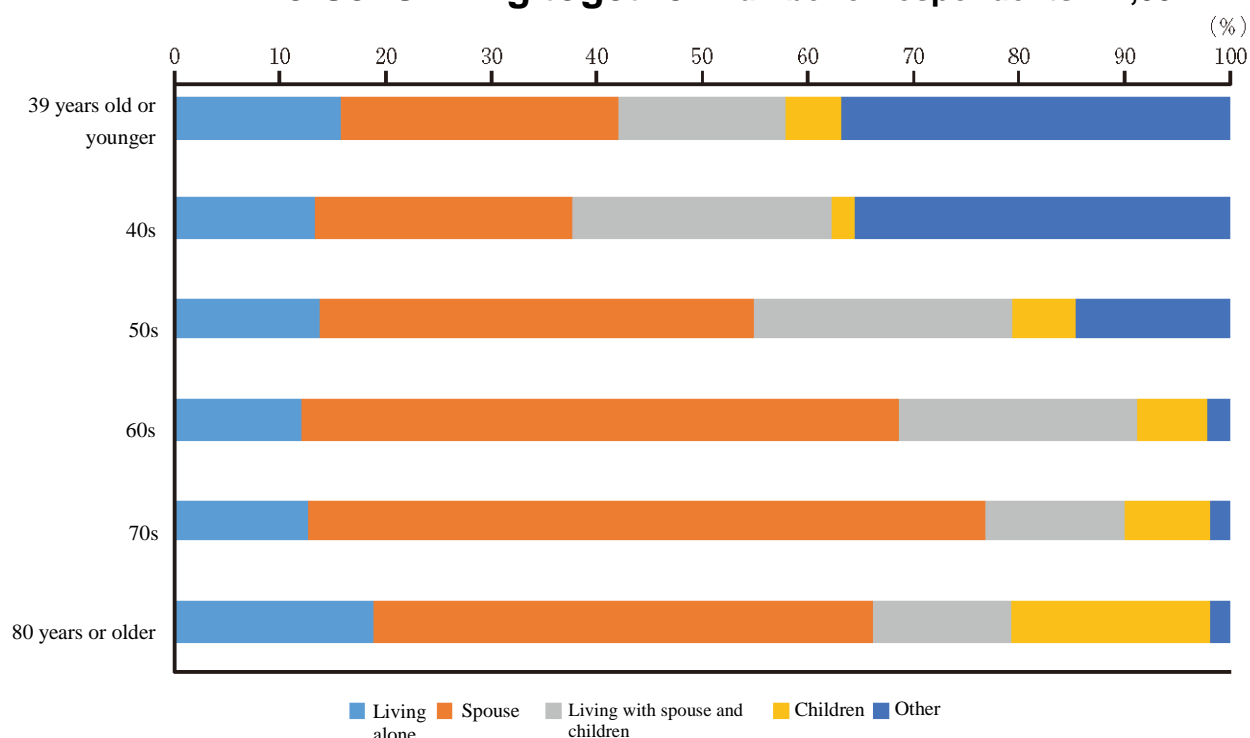
(%)



As the reason for the change of the ostomy appliance, "Recommended at the stoma clinic (outpatient)" was the most common, followed by "Recommended by a dealer."

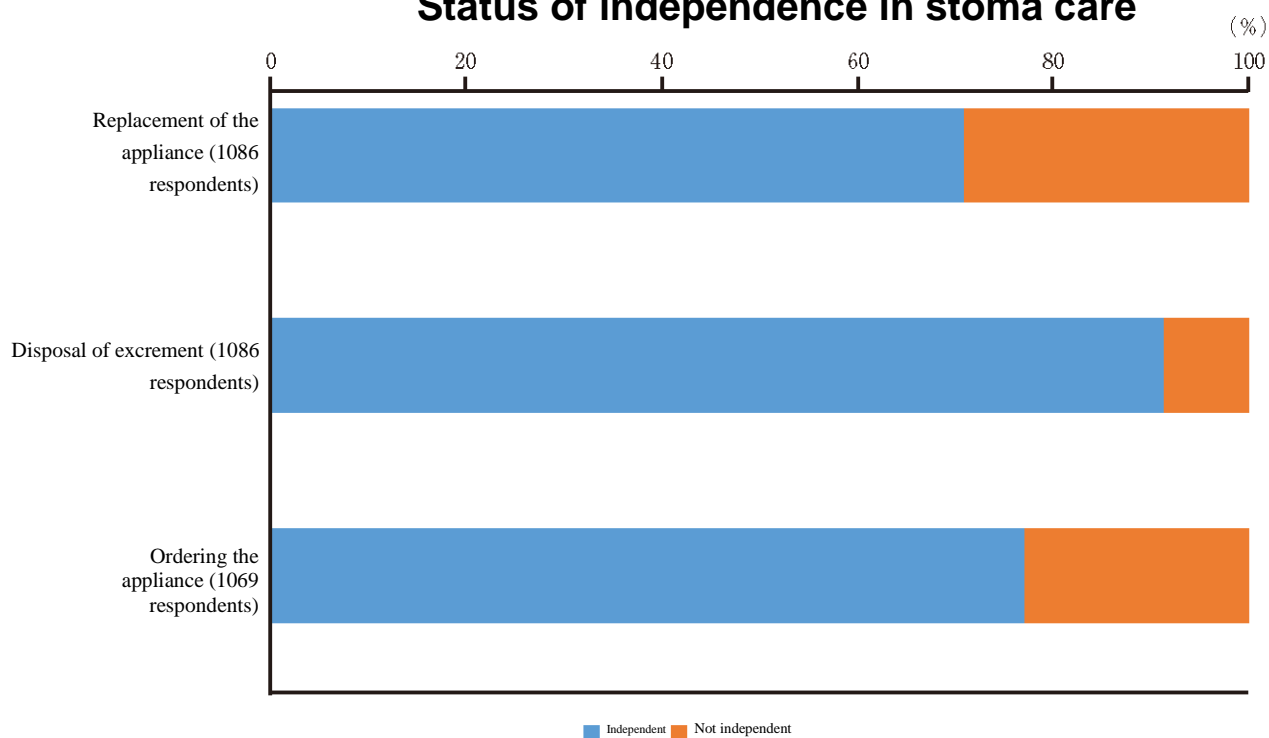
7. Way of living and status of independence in care

Persons living together Number of respondents = 1,051



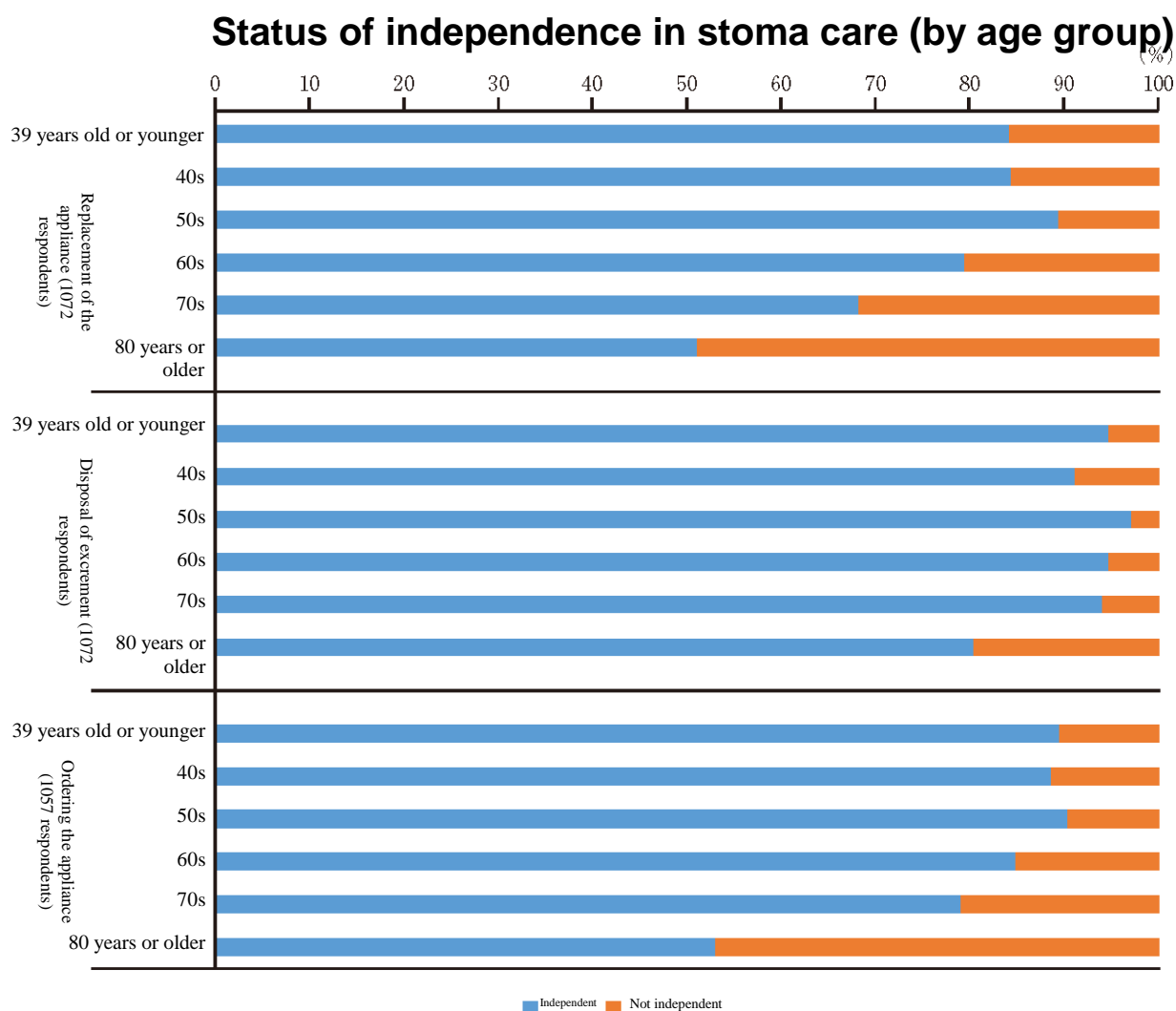
Among those aged 60 years or older, approximately 70% of the respondents were living with their spouse and 14% were living alone.

Status of independence in stoma care



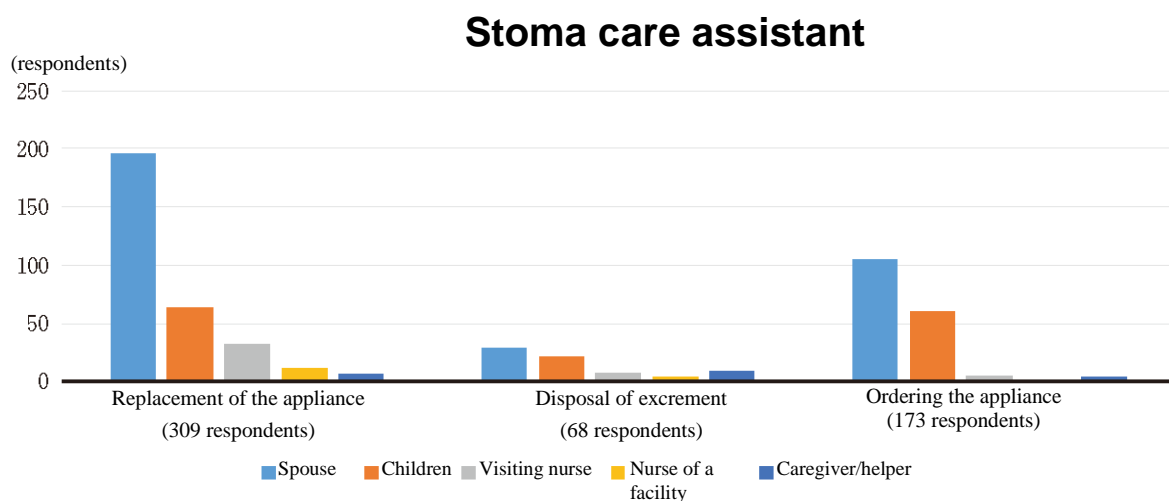
* The term “independent” in this context means that a respondent conducts everything by himself or herself.

* Disposal of excrement: To take out excrement from the ostomy bag, or to replace the bag.



For replacement of the appliance and ordering of the appliance, the proportion of those who are independent decreases to about half among the respondents aged 80 years or older.

For disposal of excrement, 80% or more of respondents were independent even among the respondents aged 80 years or older.



Spouses were the most common caregivers for those who necessitated partial or full assistance in the stoma care, followed by children.