A report on research into the anxieties and burdens of cancer survivors

The views of 7,885 people who faced up to cancer

Joint Study Group on the Sociology of Cancer

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Introduction

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Introduction

“A research project that anyone would regard as vital, but one which nobody had actually carried out”. That’s how one medical specialist summed up the research presented in this volume. To let cancer patients speak about their anxieties in their own words, on a nationwide scale, and whilst protecting their privacy, and then to scientifically analyse and compile the results. That was the substance of this research. The results will be put to use in improving the quality of life of people suffering from cancer.

A draft for the questionnaire was drawn up by specialists in medicine and questionnaire research, and this was then finalized with the cooperation of the institutions taking part in the survey in 53 locations, and 15 patient and patient support groups. The pivotal part of the research was to elicit freely written responses from patients, describing in their own words what their anxieties as cancer patients are, and what they feel is necessary to alleviate their anxieties. In addition to various background factors, a considerable number of additional supplementary questions were added. The survey was undertaken with the permission of the ethical review committees at each facility, and with the informed consent of the respondents; their responses were sent to the dedicated think tank dealing with analyzing the results, and the utmost care to protect the patients’ privacy was taken.

A total number of 7,885 cancer patients took part in the survey. The think tank staff objectively processed each and every response, sifting through 20,000 descriptions of the patients’ anxieties and burdens. These were then divided into 15 primary categories, 35 secondary categories, 129 tertiary categories, and 623 microcategories, and compiled into a database. Another 7,000 suggestions concerning measures to alleviate patients’ anxieties were also elicited. This interim report analyses the categorized data in the light of a variety of background factors. At a later stage, we also plan to compile every single one of the 20,000 responses into a few lines of text, and add data on patients’ anxieties broken down by type of cancer. We will then be able to put forward some useful suggestions about alleviating patients’ anxieties, and play a role in promoting the development and upgrading of the necessary tools.

How exactly can this survey help to improve the quality of life of cancer patients?

First of all, it will help by letting people who have recently contracted cancer and their families know what sort of anxieties those faced with cancer experience, and how these sufferers have dealt with their anxieties.

Second, it will help medical technicians and people in government who deal with cancer to gain a real understanding of patients’ anxieties. It is hoped that this will enable the resolution of these anxieties during the medical care process, and lead to a more appropriate approach to consulting. It may also enable the development of new medical techniques to alleviate symptoms, side effects and after effects.

Finally, the survey will help society to appreciate the immediacy of cancer patients’ anxieties. In our “cancer age”, in which every other man and one woman in three contracts the disease, society’s understanding is essential for the development of a social infrastructure that will lead to the alleviation of patients’ anxieties.

This document represents the interim report on the survey. Once we have completed the database of patients’ anxieties, we plan to promote further research into the development of tools that will help to alleviate these anxieties, and research into the improvement of medical resources.

1 Outline of the questionnaire survey

(1) Institutions conducting the survey:

53 medical institutions, and 15 patient/patient-support groups

(2) Ethical considerations of the questionnaire:

- Privacy was protected using anonymity methods with which it is not possible to determine individual names of respondents.
- Approval of ethical review committees and the written consent of respondents were obtained in general.

(3) Date of the survey:

April to December 2003

(4) Survey respondents:

(At medical institutions)

Outpatients with cancer who were aged 20 years or over,

（At patient/patient-support groups）

People aged 20 years or over who have experienced cancer and belong to patient/patient-support groups, and who gave their prior consent.

(5) Number of responses received

（Overall）

Number of questionnaires sent out: 12,345
Number of questionnaires returned: 7,885
Response rate: 63.9%

Note 1. Of the 7,885 responses received, 48 were not fully completed, or were returned by patients whose age or illness was not within the range of the survey. These are presented as reference opinions in Appendix 5. They were excluded in processing the statistics, in which the parameter of 7,387 responses was used.

（Medical institutions）

Number of questionnaires sent out: 10,200
Number of questionnaires returned: 7,272（the statistical parameter used as in Note 1. was 7,235 responses）
Response rate: 71.3%

（Patient/patient-support groups）

Number of questionnaires sent out: 2,145
Number of questionnaires returned: 613 （the statistical parameter used as in Note 1. was 602 responses)
Response rate: 28.6%

Note 2. In general, this report uses the parameter of 7,837 responses in the calculations made. In order to make them more easily understood, some of the tables and graphs use the number of respondents or responses to individual questions as their parameters.

2 Tabulated results of the questionnaire

Tabulated results compiled in line with the questionnaire sheet entitled Research into the Anxieties and Burdens of Cancer Sufferers (please refer to Appendix 6.) with the exception of the free answer section in Question7.

Question 1. At what age were you diagnosed as suffering from cancer? (By age group）

Age at diagnosis	Number	(%)
1. 20s	110	(1.4%)
2. 30s	435	(5.6%)
3. 40s	1,184	(15.1%)
4. 50s	2,036	(26.0%)
5. 60s	2,369	(30.2%)
6. 70s	1,427	(18.2%)
7. 80s	125	(1.6%)
8. 90s	4	(0.1%)
No response	147	(1.9%)
Total	7,837	(100.0%)

91.2% of respondents were 40 years of age or over, illustrating that cancer is a disease of older people.

Question 2. What type of cancer were you diagnosed with? Please circle one type.

Body part	Number	(%)
1. Brain	4	(0.1%)
2. Pharynx/larynx	271	(3.5%)
3. Lung	749	(9.6%)
4. Esophagus	230	(2.9%)
5. Stomach	1,046	(13.3%)
6. Duodenum/small intestine	35	(0.4%)
7. Colon/rectum	1,055	(13.5%)
8. Liver	255	(3.3%)
9. Biliary tract/gall bladder	87	(1.1%)
10. Pancreas	102	(1.3%)
11. Kidney/adrenal gland	76	(1.0%)
12. Urinary bladder	120	(1.5%)
13. Skin	29	(0.4%)
14. Mouth/Tongue	100	(1.3%)
15. Uterus	498	(6.4%)
16. Ovary/fallopian tube	156	(2.0%)
17. Breast	1,904	(24.3%)
18. Prostate	302	(3.9%)
19. Testicle	14	(0.2%)
20. Thyroid gland	90	(1.1%)
21. Leukemia	162	(2.1%)
22. Myeloma	32	(0.4%)
23. Bone	8	(0.1%)
24. Soft tissue (muscle/fat)	30	(0.4%)
25. Lymphoma	197	(2.5%)
26. Other	102	(1.3%)
No response	183	(2.3%)
Total	7,837	(100.0%)

The most common forms of cancer are, in order of occurrence, breast cancer, colon/rectum cancer, stomach cancer, lung cancer, uterus cancer, prostate cancer, and pharynx/larynx cancer. As the respondents to the survey are outpatients the pattern they provide resembles the number of people living in society and who have experienced cancer more accurately than just the number of people

Question 3. Have you subsequently been told by your doctor that a recurrence or spreading of the cancer has been detected?

Recurrence/spread	Number	(%)
1. Yes	1,852	(23.6%)
2. No	5,744	(73.3%)
No response	241	(3.1%)
Total	7,837	(100.0%)

Recurrence or spreading of the cancer is detected in around one quarter of cases. Those cases in which recurrence or spreading has not been detected includes patients who are under observation after therapy, or who are regarded as being virtually cured after 5 to 10 years following therapy. They may include cases in which patients have not been informed that their cancer has recurred or spread.

Supplementary question 3-1. Circle all the parts of your body in which recurrence or spreading has been detected（as many as applicable）.

Number of respondents=1,852

Region of recurrence/metastasis	Number	(%)
1. Brain/meninges	85	(4.6%)
2 . Pharynx/larynx	45	(2.4%)
3. Lung/pleura	498	(26.9%)
4. Esophagus	24	(1.3%)
5. Stomach	88	(4.8%)
6. Duodenum/Small intestine	21	(1.1%)
7. Colon/rectum	149	(8.0%)
8. Liver	455	(24.6%)
9. Biliary tract/gall bladder	16	(0.9%)
10. Pancreas	26	(1.4%)
11. Kidney/adrenal gland	42	(2.3%)
12. Urinary bladder	68	(3.7%)
13. Skin	27	(1.5%)
14. Mouth/tongue	11	(0.6%)
15. Uterus	31	(1.7%)
16. Ovary/fallopian tube	36	(1.9%)
17. Breast	120	(6.5%)
18. Prostate	41	(2.2%)
19. Testicle	0	―
20. Thyroid gland	18	(1.0%)
21. Bone marrow	32	(1.7%)
22. Lymph node (gland)	433	(23.4%)
23. Bone	271	(14.6%)
24. Soft tissue (muscle/fat)	15	(0.8%)
25. Spinal cord	29	(1.6%)
26. Peritoneum	46	(2.5%)
27. Pericardium/pericardial membrane	2	(0.1%)
28. Other	60	(3.2%)
No response	26	(1.4%)

The most commonly affected parts of the body are, in order of occurrence, lung/pleura, liver, lymph node (gland), and bones; these are all solid cancer sites.

Question 4. Circle whichever of the following best describes the current state of your treatment.

State of treatment	Number	(%)
1. Undergoing continuous treatment	2,820	(36.0%)
2. Undergoing regular tests	4,758	(60.7%)
3. Other	135	(1.7%)
No response	124	(1.6%)
Total	7,837	(100.0%)

Reflects the answers to Question 3. about recurrence and spreading.

Question 5. Circle all of the types of treatment that you have undergone so far at medical institutions (as many as applicable).

Number of respondents＝7,837

Treatment	Number	(%)
1. Surgery	6,013	(76.7%)
2. Endoscopic, thoracoscopic or laparoscopic surgery	1,968	(25.1%)
3. Drug therapy (anticancer drugs or hormone drugs etc)	4,601	(58.7%)
4. Irradiation therapy	2,374	(30.3%)
5. Other	121	(1.5%)
No response	171	(2.2%)

The sizeable proportion of people undergoing endoscopic, thoracoscopic or laparoscopic surgery shows the recent advances in treatment.

Question 6. Circle the statement below that most accurately describes your current lifestyle.

Daily life	Number	(%)
1. I have no particular symptoms and can participate in social activities. I am not constrained by my illness or treatments, and I can still perform activities that I was performing before I contracted cancer.	4,412	(56.3%)
2. I have mild symptoms. I am not always capable of performing work that requires physical effort (physical labor), but can walk and perform light and sedentary work such as housework or office work.	2,649	(33.8%)
3. I can walk and take care of myself, but sometimes I need the help of others. I cannot perform light work, but am up and out of bed for at least half the day.	412	(5.3%)
4. I can take care of myself to a certain extent, but often need someone's help. I am in bed for at least half the day.	188	(2.4%)
5. I can not take care of myself and always need someone's help. I stay in bed all day.	16	(0.2%)
No response	160	(2.0%)
Total	7,837	(100.0%)

Since the respondents are outpatients most of them have no particular symptoms and can behave much as they did before falling ill, or are at least able to perform some light work.

Question 7. What did you become anxious about? Circle all of the answers applicable.

Number of respondents=7,837

Worry/bother	Number	(%)
1. Physical suffering including pain side-effects and after-effects	3,770	(48.1%)
2. Psychological issues such as depression, worry or fear	4,144	(52.9%)
3. Family/household issues such as conjugal relations or parent-child relations	2,277	(29.1%)
4. Societal issues such as employment, position, social relations etc.	1,608	(20.5%)
5. Relationships with medical staff	628	(8.0%)
6. Economic issues such as income, treatment costs and savings for the future	2,752	(35.1%)
7. Future way of life or the meaning of life	2,949	(37.6%)
8. Other	180	(2.3%)
No response	873	(11.1%)

Though a comparison with the replies to the free answer section is necessary, there is clearly an array of anxieties, including physical, mental, and social concerns, as well as worries about the relationship between patients and medical staff.

Question 8. Did you discuss the anxieties cited in question 7? Circle each of the applicable numbers for each period.

(a. Around the time of diagnosis)

Discusses anxieties or otherwise	Number	(%)
1. Didn't want to discuss them with anybody	1,570	(20.0%)
2. Discussed or attempted to discuss	5,036	(64.3%)
No response	1,231	(15.7%)
Total	7,837	(100.0%)

Question 9. If you circled 2 (discussed or attempted to discuss) in Question 8, please indicate all of the people or institutions you discussed your anxieties with listed below (as many as applicable).

Number of respondents＝4,266

	Worries dissipated		Worries did not dissipate		They did not talk with me	
	Number	(%)	Number	(%)	Number	(%)
1. Family	2,976	(59.1%)	579	(11.5%)	11	(0.2%)
2. Friends/acquaintances	1,138	(22.6%)	193	(3.8%)	5	(0.1%)
3. Relatives	817	(16.2%)	144	(2.9%)	4	(0.1%)
4. Colleague	272	(5.4%)	54	(1.1%)	5	(0.1%)
5. Patient with same illness met in hospital	487	(9.7%)	53	(1.1%)	1	(0.0%)
6. Patient/self-help group	120	(2.4%)	17	(0.3%)	0	－
7. One's own doctor	1,288	(25.6%)	156	(3.1%)	9	(0.2%)
8. Nurse	331	(6.6%)	49	(1.0%)	3	(0.1%)
9. Other people	111	(2.2%)	7	(0.1%)	1	(0.0%)
a. Hospital counseling room etc.	49	(1.0%)	12	(0.2%)	1	(0.0%)
b. Prefectural or municipal consultation services	24	(0.5%)	6	(0.1%)	2	(0.0%)
c. Other institutions	39	(0.8%)	10	(0.2%)	1	(0.0%)
No response	878	(17.4%)	878	(17.4%)	878	(17.4%)

	I could not consult them		I could not find anyone to talk to	
	Number	(%)	Number	(%)
1. Family	18	(0.4%)	7	(0.1%)
2. Friends/acquaintances	27	(0.5%)	4	(0.1%)
3. Relatives	15	(0.3%)	5	(0.1%)
4. Colleague	8	(0.2%)	2	(0.0%)
5. Patient with same illness met in hospital	4	(0.1%)	5	(0.1%)
6. Patient/self-help group	7	(0.1%)	9	(0.2%)
7. One's own doctor	24	(0.5%)	4	(0.1%)
8. Nurse	5	(0.1%)	0	－
9. Other people	1	(0.0%)	4	(0.1%)
a. Hospital counseling room etc.	4	(0.1%)	3	(0.1%)
b. Prefectural or municipal consultation services	4	(0.1%)	7	(0.1%)
c. Other institutions	2	(0.0%)	6	(0.1%)
No response	878	(17.4%)	878	(17.4%)

(b. From diagnosis until the present time)

Discusses anxieties or otherwise	Number	(%)
1. Didn't want to discuss them with anybody	1,099	(14.0%)
2. Discussed or attempted to discuss	4,266	(54.4%)
No response	2,472	(31.5%)
Total	7,837	(100.0%)

Number of respondents＝4,266

	Worries dissipated		Worries did not dissipate		They did not talk with me	
	Number	(%)	Number	(%)	Number	(%)
1. Family	2,279	(53.4%)	296	(6.9%)	6	(0.1%)
2. Friends/acquaintances	1,076	(25.2%)	127	(3.0%)	2	(0.0%)
3. Relatives	653	(15.3%)	79	(1.9%)	4	(0.1%)
4. Colleague	212	(5.0%)	35	(0.8%)	2	(0.0%)
5. Patient with same illness met in hospital	876	(20.5%)	74	(1.7%)	1	(0.0%)
6. Patient/self-help group	257	(6.0%)	18	(0.4%)	1	(0.0%)
7. One's own doctor	1,489	(34.9%)	167	(3.9%)	16	(0.4%)
8. Nurse	471	(11.0%)	54	(1.3%)	3	(0.1%)
9. Other people	102	(2.4%)	8	(0.2%)	1	(0.0%)
a. Hospital counseling room etc.	65	(1.5%)	12	(0.3%)	2	(0.0%)
b. Prefectural or municipal consultation services	21	(0.5%)	6	(0.1%)	1	(0.0%)
c. Other institutions	51	(1.2%)	14	(0.3%)	0	―
No response	792	(18.6%)	792	(18.6%)	792	(18.6%)

	I could not consult them		I could not find anyone to talk to	
	Number	(%)	Number	(%)
1. Family	14	(0.3%)	3	(0.1%)
2. Friends/acquaintances	17	(0.4%)	3	(0.1%)
3. Relatives	9	(0.2%)	3	(0.1%)
4. Colleague	9	(0.2%)	1	(0.0%)
5. Patient with same illness met in hospital	10	(0.2%)	3	(0.1%)
6. Patient/self-help group	11	(0.3%)	8	(0.2%)
7. One's own doctor	33	(0.8%)	5	(0.1%)
8. Nurse	9	(0.2%)	2	(0.0%)
9. Other people	1	(0.0%)	6	(0.1%)
a. Hospital counseling room etc.	9	(0.2%)	5	(0.1%)
b. Prefectural or municipal consultation services	4	(0.1%)	4	(0.1%)
c. Other institutions	1	(0.0%)	6	(0.1%)
No response	792	(18.6%)	792	(18.6%)

(c. Currently)

Discusses anxieties or otherwise	Number	(%)
1. Didn’t want to discuss them with anybody	1,276	(16.3%)
2. Discussed or attempted to discuss	3,526	(45.0%)
No response	3,035	(38.7%)
Total	7,837	(100.0%)

Number of respondents＝3,526

	Worries dissipated		Worries did not dissipate		They did not talk with me	
	Number	(%)	Number	(%)	Number	(%)
1. Family	1,840	(52.2%)	236	(6.7%)	6	(0.2%)
2. Friends/acquaintances	826	(23.4%)	96	(2.7%)	1	(0.0%)
3. Relatives	466	(13.2%)	61	(1.7%)	5	(0.1%)
4. Colleague	156	(4.4%)	24	(0.7%)	5	(0.1%)
5. Patient with same illness met in hospital	568	(16.1%)	56	(1.6%)	0	－
6. Patient/self-help group	196	(5.6%)	15	(0.4%)	0	－
7. One’s own doctor	1,214	(34.4%)	133	(3.8%)	1	(0.0%)
8. Nurse	262	(7.4%)	31	(0.9%)	5	(0.1%)
9. Other people	87	(2.5%)	9	(0.3%)	0	－
a. Hospital counseling room etc.	38	(1.1%)	9	(0.3%)	1	(0.0%)
b. Prefectural or municipal consultation services	22	(0.6%)	6	(0.2%)	3	(0.1%)
c. Other institutions	49	(1.4%)	16	(0.5%)	1	(0.0%)
No response	692	(19.6%)	692	(19.6%)	692	(19.6%)

	I could not consult them		I could not find anyone to talk to	
	Number	(%)	Number	(%)
1. Family	17	(0.5%)	3	(0.1%)
2. Friends/acquaintances	13	(0.4%)	3	(0.1%)
3. Relatives	8	(0.2%)	1	(0.0%)
4. Colleague	3	(0.1%)	4	(0.1%)
5. Patient with same illness met in hospital	4	(0.1%)	2	(0.1%)
6. Patient/self-help group	8	(0.2%)	4	(0.1%)
7. One’s own doctor	31	(0.9%)	7	(0.2%)
8. Nurse	7	(0.2%)	0	－
9. Other people	0	－	9	(0.3%)
a. Hospital counseling room etc.	9	(0.3%)	8	(0.2%)
b. Prefectural or municipal consultation services	4	(0.1%)	5	(0.1%)
c. Other institutions	3	(0.1%)	10	(0.3%)
No response	692	(19.6%)	692	(19.6%)

Two thirds of patients have alleviated their anxieties by talking to somebody.

The order in which patients’ discussed their anxieties was: with their family, their doctor, and with their friends or acquaintances. This was the same at all three stages — around the time of diagnosis, from diagnosis to the present, and currently.

Question 10. What do you think is needed in order to provide some relief from the anxieties you had or have now? Write whatever you like.

Number of respondents＝7,837

Desired assistance	Number	(%)
1. Relationships with medical staff	1,469	(18.7%)
2. Counseling/psychological care	885	(11.3%)
3. Economic assistance with medical costs etc.	416	(5.3%)
4. Supply and disclosure of information	470	(6.0%)
5. Interaction with similar patients/patient groups	636	(8.1%)
6. Decisions made with own efforts	1,432	(18.3%)
7. Cooperation, understanding and support from family	648	(8.3%)
8. Cooperation, understanding and support from friends	204	(2.6%)
9. Demands to the administration or medical institutions	514	(6.6%)
10.Medical progress	252	(3.2%)
11.Religion	70	(0.9%)
12.Work environment	46	(0.6%)
13.Other	154	(2.0%)
No response	2,940	(37.5%)

A good relationship with medical staff was the most commonly cited need, closely followed by a need to solve the situation through one’s own efforts. These were closely followed by the need for: psychological care; the cooperation, understanding and support of families; interaction with sufferers of the same disease, and patients groups; demands to be made towards government and medical institutions, and the open provision of information.

Question 11. Please indicate your date of birth. (By age group)

Age	Number	(%)
1. 20s	45	(0.6%)
2. 30s	258	(3.3%)
3. 40s	802	(10.2%)
4. 50s	1,809	(23.1%)
5. 60s	2,395	(30.6%)
6. 70s	2,073	(26.5%)
7. 80s	272	(3.5%)
8. 90s	6	(0.1%)
No response	177	(2.3%)
Total	7,837	(100.0%)

Showing the age of patients at the time of diagnosis, the breakdown of current ages indicates that 93.9% of patients are over 40 years of age, and 83.6% are over 50.

Question 12. Please indicate your gender.

Sex	Number	(%)
1.Male	3,531	(45.1%)
2.Female	4,220	(53.8%)
No response	86	(1.1%)
Total	7,837	(100.0%)

Question 13. Please tell us about your family.

Question 13-1. Are you currently married? Circle the appropriate response.

Marital status	Number	(%)
1.Single	429	(5.5%)
2.Married	6,252	(79.8%)
3.Divorced/ widowed	1011	(12.9%)
No response	145	(1.9%)
Total	7,837	(100.0%)

Question 13-2. Do you currently live with someone? Indicate their relationship to you by circling all the appropriate responses.

No. of respondents＝7,837

Co-habitants	Number	(%)
1.Live alone	658	(8.4%)
2.Spouse (husband or wife)	6,040	(77.1%)
3.Father	239	(3.0%)
4.Mother	603	(7.7%)
5.Spouse's father	166	(2.1%)
6.Spouse's mother	367	(4.7%)
7.Sibling(s)	173	(2.2%)
8.Spouse's sibling(s)	27	(0.3%)
9.Child(ren)	3,667	(46.8%)
10.Child's spouse	763	(9.7%)
11.Grandchild(ren)	900	(11.5%)
12.Other relatives	41	(0.5%)
13.Other	24	(0.3%)
No response	138	(1.8%)

Just under one tenth (8.4%) of cancer sufferers live alone.

Question 13-3. The following question is directed at those who have children. Please circle the appropriate response.

Child(ren)	Number	(%)
1.Youngest not yet school age	138	(1.8%)
2.Youngest attends primary or junior high school	417	(5.3%)
3.Youngest attends high school	228	(2.9%)
4.All have finished schooling but are attending tertiary institutions	401	(5.1%)
5.All are independent with jobs and/or have married	5,023	(64.1%)
6.They are not yet working or married	268	(3.4%)
7.Other	33	(0.4%)
No response	1,329	(17.0%)
Total	7,837	(100.0%)

64.1% of respondents replied that all of their children were either in full time employment or married. 15.1% of respondents' children were still at school or university – and therefore still a financial burden on their parents.

Question 14. Please tell us about your occupation.

Question 14-1. Which of the occupations in the chart below best describes your state of employment at the time you were diagnosed as suffering from cancer?

At time of diagnosis

Employment	Number	(%)
1. Self-employed	390	(5.0%)
2. Sole trader	372	(4.7%)
3. Employed in family business	297	(3.8%)
4. Executive/director	291	(3.7%)
5. Private company employee	1,335	(17.0%)
6. Public servant	372	(4.7%)
7. Part-time/casual	798	(10.2%)
8. Side-job	40	(0.5%)
9. Full-time housewife	1,135	(14.5%)
10.Student	14	(0.2%)
11.Unemployed	1171	(14.9%)
12.Other	140	(1.8%)
No response	1,482	(18.9%)
Total	7,837	(100.0%)

Current employment

Employment	Number	(%)
1. Self-employed	291	(3.7%)
2. Sole trader	306	(3.9%)
3. Employed in family business	238	(3.0%)
4. Executive/director	202	(2.6%)
5. Private company employee	749	(9.6%)
6. Public servant	251	(3.2%)
7. Part-time/casual	532	(6.8%)
8. Side-job	29	(0.4%)
9. Full-time housewife	1,435	(18.3%)
10.Student	5	(0.1%)
11.Unemployed	2158	(27.5%)
12.Other	122	(1.6%)
No response	1,519	(19.4%)
Total	7,837	(100.0%)

Since around half of the respondents were in their 50s or 60s there was an increase in the number of those with no occupation, and housewives.

Question 14-2. Which of the descriptions in the chart below best describes the nature of your occupation?

At time of diagnosis

Industry	Number	(%)
1. Agriculture, forestry, fisheries	216	(2.8%)
2. Transport, telecommunication, security	186	(2.4%)
3. Industrial production	572	(7.3%)
4. Service	361	(4.6%)
5. Retail	610	(7.8%)
6. Clerical	676	(8.6%)
7. Administration	475	(6.1%)
8. Professional	483	(6.2%)
9. Other	274	(3.5%)
No response	3,984	(50.8%)
Total	7,837	(100.0%)

Currently

Industry	Number	(%)
1. Agriculture, forestry, fisheries	171	(2.2%)
2. Transport, telecommunication, security	116	(1.5%)
3. Industrial production	319	(4.1%)
4. Service	222	(2.8%)
5. Retail	408	(5.2%)
6. Clerical	468	(6.0%)
7. Administration	296	(3.8%)
8. Professional	382	(4.9%)
9. Other	224	(2.9%)
No response	5,231	(66.7%)
Total	7,837	(100.0%)

Question 14-3. Please circle the appropriate response regarding the company you were working at or the business you were running at the time of diagnosis.

Employed by someone	Number	(%)
1. Still working	1,249	(47.6%)
2. Retired	229	(8.7%)
3. Resigned voluntarily	799	(30.5%)
4. Dismissed	111	(4.2%)
5. Other	237	(9.0%)
Total respondents	2,625	(100.0%)

Self/family employed, sole business	Number	(%)
1. Still operating business	694	(68.0%)
2. Suspension of business	79	(7.7%)
3. Not operating	58	(5.7%)
4. Discontinued business	135	(13.2%)
5. Under new ownership	41	(4.0%)
6. Other	14	(1.4%)
Total respondents	1,021	(100.0%)

The respondents are represented as a population parameter proportion.

3,646 people responded to question 14-3. Of these, 2,625 people were employed, and 1,021 people were self-employed or running a business by themselves or with their family. Though it is not possible to tell if this is a direct consequence of contracting cancer, 34.7% of employed respondents subsequently retired voluntarily or were dismissed. The fact that 30.7% of self-employed respondents had suspended their businesses, were not working, had closed down their business or entrusted its running to someone else, suggests that

Question 15. What was your after tax income during the past year? (Including pensions and allowances from family members.)

Income (yen)	Number	(%)
1. Less than 1.2 million	448	(5.7%)
2. 1.2 ~ 3 million	1,743	(22.2%)
3. 3 ~ 4 million	1,300	(16.6%)
4. 4 ~ 5 million	800	(10.2%)
5. 5 ~ 6 million	612	(7.8%)
6. 6 ~ 8 million	810	(10.3%)
7. 8 ~ 10 million	586	(7.5%)
8. 10 ~ 20 million	549	(7.0%)
9. 20 million or more	89	(1.1%)
No response	900	(11.5%)
Total	7,837	(100.0%)

Annual incomes of less than 4 million yen accounted for 44.5% of responses. This is probably because most cancer patients contract the disease after retirement, and many of them are living off pensions.

(Reference) Income according to age

Income (yen)	1. 20s	2. 30s	3. 40s	4. 50s	5. 60s	6. 70s	7. 80s	8. 90s	No response	Total
1. Less than 1.2 million	7	16	25	75	135	145	28	—	17	448
2. 1.2 ~ 3 million	14	28	75	237	707	578	69	1	34	1,743
3. 3 ~ 4 million	7	31	61	178	486	462	55	—	20	1,300
4. 4 ~ 5 million	5	45	68	157	237	248	28	—	12	800
5. 5 ~ 6 million	3	36	83	174	171	124	11	—	10	612
6. 6 ~ 8 million	3	36	184	284	176	100	11	—	16	810
7. 8 ~ 10 million	1	17	116	275	111	54	5	1	6	586
8. 10 ~ 20 million	2	13	110	231	102	75	9	—	7	549
9. 20 million or more	—	1	14	34	24	15	—	—	1	89
No response	3	35	66	164	246	272	56	4	54	900
Total	45	258	802	1,809	2,395	2,073	272	6	177	7,837

Question 16A. How much did you pay to medical institutions?

Amount paid (yen)	Number	(%)
1. Less than 500 thousand	3,688	(47.1%)
2. 500 thousand ~ 1 million	892	(11.4%)
3. 1 million ~ 1.5 million	318	(4.1%)
4. 1.5 ~ 2 million	131	(1.7%)
5. 2 ~ 2.5 million	52	(0.7%)
6. 2.5 ~ 3 million	36	(0.5%)
7. 3 ~ 3.5 million	26	(0.3%)
8. 3.5 ~ 4 million	4	(0.1%)
9. 4 ~ 4.5 million	4	(0.1%)
10. 4.5 ~ 5 million	2	(0.0%)
11. 5 ~ 5.5 million	3	(0.0%)
12. 5.5 ~ 6 million	2	(0.0%)
13. 6 ~ 6.5 million	4	(0.1%)
14. 6.5 ~ 7 million	1	(0.0%)
15. 7 ~ 7.5 million	2	(0.0%)
17. 8 ~ 8.5 million	2	(0.0%)
18. 8.5 ~ 9 million	1	(0.0%)
23. 11 ~ 11.5 million	1	(0.0%)
30. 14.5 ~ 15 million	1	(0.0%)
No response	2,667	(34.0%)
Total	7,837	(100.0%)

Both the amounts paid to medical institutions and the amounts paid elsewhere for treatment were less than 500,000 yen in many cases. However, as the majority of respondents were retired people aged 60 or over and living off pensions, the financial burden is probably considerable.

Question 16D. How much did you pay, other than to medical institutions, for treatment or the alleviation of after effects?

Amount paid (yen)	Number	(%)
1. Less than 500 thousand	1,173	(15.0%)
2. 500 ~1 million	177	(2.3%)
3. 1 million ~ 1.5 million	81	(1.0%)
4. 1.5 million ~ 2 million	34	(0.4%)
5. 2 million ~ 2.5 million	22	(0.3%)
6. 2.5 million ~ 3 million	3	(0.0%)
7. 3 million ~ 3.5 million	11	(0.1%)
8. 3.5 million ~ 4 million	4	(0.1%)
9. 4 million ~ 4.5 million	2	(0.0%)
12. 5.5 million ~ 6 million	1	(0.0%)
16. 7.5 million ~ 8 million	1	(0.0%)
No response	6,328	(80.7%)
Total	7,837	(100.0%)

3 Compiling the responses in the free answer section into a database

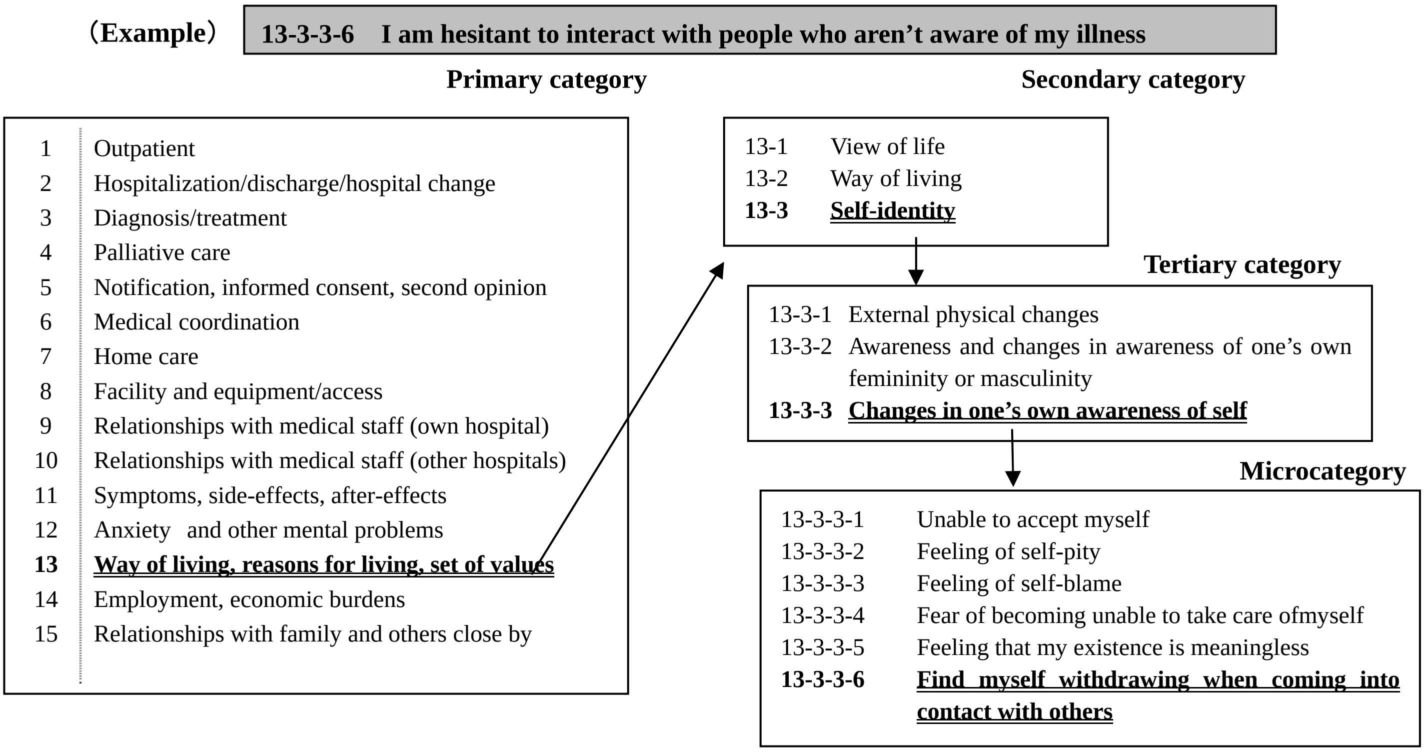
The two pivotal questions in the survey sought to elucidate what anxieties patients felt upon undergoing diagnosis and treatment, and what they felt was needed to alleviate their anxieties and burdens. Respondents were asked to freely answer these questions in their own words.

The free answer format forces the respondents to put their thoughts into writing, and thus imposes on them a burden in terms of time and effort, which may be perceived as a drawback to carrying out such a questionnaire survey. Nonetheless, we used this format in order to gain a first-hand insight into the lifestyles of cancer patients discharged from hospital and their relationships with the people around them − aspects about which medical practitioners have hitherto known very little. When the survey was conducted at medical institutions, the process of obtaining a signed form of consent from patients and thorough explanations of the purpose and the special characteristics of the survey helped respondents to better understand the project. The replies that we received were even more detailed than we had expected.

From our point of view too, the free answer format led to a considerable amount of hard work in analyzing the results of the survey. We distilled the assertions of respondents from the free answer sections, and then classified and analysed them. The method used for classifying the responses was as follows. First, we picked out some keywords concerning the anxieties and burdens detailed in the free answer sections of the 7,885 response. As there were three to four keywords in most of the responses, the eventual number of anxieties or burdens extracted reached a total of 25,952 pieces of data, each of which consisted of two or three lines of text.

The data was then classified and labeled, and finally a database was created consisting of 15 primary categories, 35 secondary categories, 129 tertiary categories, and 623 microcategories. Figure 3.1 provides an example of the construction of the database, in this case the primary category entitled “Way of living, reasons for living, set of values”. The headings of all of the primary, secondary, tertiary and microcategories are provided in Appendix 1.

Fig.3.1 Example of the database structure



(Example) **13-3-3-6 I am hesitant to interact with people who aren’t aware of my illness**

Primary category

1	Outpatient
2	Hospitalization/discharge/hospital change
3	Diagnosis/treatment
4	Palliative care
5	Notification, informed consent, second opinion
6	Medical coordination
7	Home care
8	Facility and equipment/access
9	Relationships with medical staff (own hospital)
10	Relationships with medical staff (other hospitals)
11	Symptoms, side-effects, after-effects
12	Anxiety and other mental problems
13	**Way of living, reasons for living, set of values**
14	Employment, economic burdens
15	Relationships with family and others close by

Secondary category

13-1	View of life
13-2	Way of living
13-3	**Self-identity**

Tertiary category

13-3-1	External physical changes
13-3-2	Awareness and changes in awareness of one’s own femininity or masculinity
13-3-3	**Changes in one’s own awareness of self**

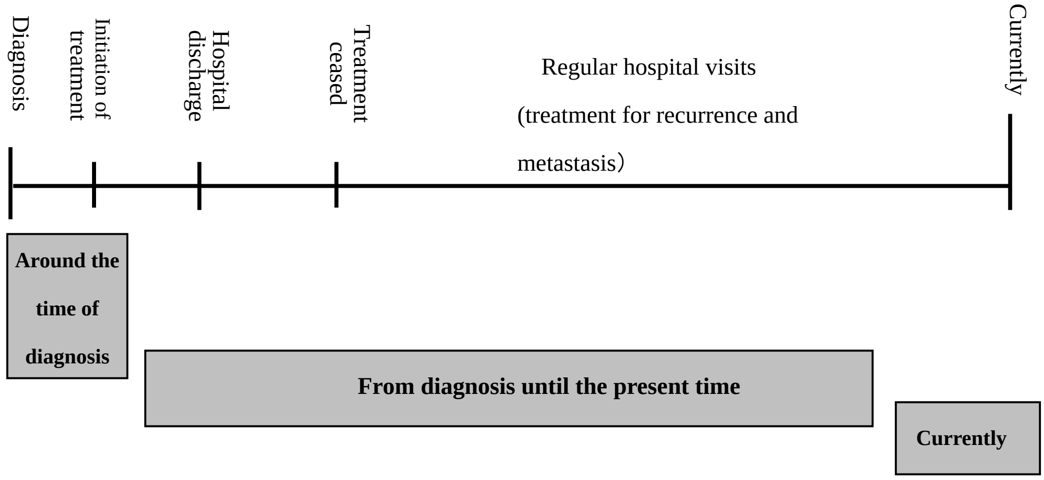
Microcategory

13-3-3-1	Unable to accept myself
13-3-3-2	Feeling of self-pity
13-3-3-3	Feeling of self-blame
13-3-3-4	Fear of becoming unable to take care ofmyself
13-3-3-5	Feeling that my existence is meaningless
13-3-3-6	**Find myself withdrawing when coming into contact with others**

4 Overall trends in anxieties and burdens of respondents

The answers to the question of what patients' anxieties were upon undergoing diagnosis and treatment were divided into three time stages − "around the time of diagnosis", "from diagnosis until the present time", and "currently"; respondents were asked to write freely about each stage.

Fig.4.1. Definition of the three time stages

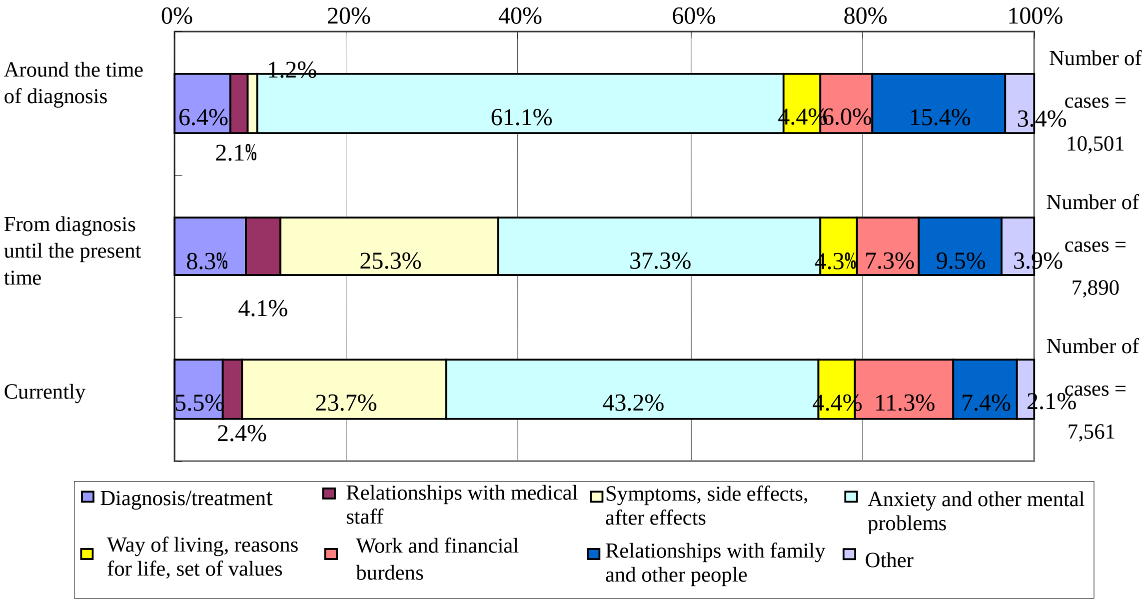


It was supposed that in the "around the time of diagnosis" stage, patients would relate the anxieties that they felt during the chaotic state of mind they experienced after having been told, amid a general lack of information, that they had cancer. The anxieties expected in the "from diagnosis until the present time" stage included patients' reflections on their diagnosis, treatment, being under observation, and any recurrence or spreading they experienced. It was supposed that the "currently" stage would elicit responses regarding the anxieties currently felt as a result of going through numerous experiences.

Tab. 4-1. Number and frequency of anxieties and burdens described during the three stages

Primary categories	Around the time of diagnosis		From diagnosis until the present time		Currently		Three stages total	
	Number of cases	(%)	Number of cases	(%)	Number of cases	(%)	Number of cases	(%)
Outpatient	82	0.8%	22	0.3%	17	0.2%	121	0.5%
Hospitalization/discharge/ hospital change	85	0.8%	93	1.2%	17	0.2%	195	0.8%
Diagnosis/treatment	669	6.4%	655	8.3%	414	5.5%	1,738	6.7%
Palliative care	76	0.7%	29	0.4%	53	0.7%	158	0.6%
Notification, informed consent, second opinion	110	1.0%	131	1.7%	50	0.7%	291	1.1%
Medical coordination	0	-	1	0.0%	1	0.0%	2	0.0%
Home care	1	0.0%	0	-	2	0.0%	3	0.0%
Facility and equipment/access	5	0.0%	24	0.3%	23	0.3%	52	0.2%
Relationships with medical staff (own hospital)	128	1.2%	280	3.5%	172	2.3%	580	2.2%
Relationships with medical staff (other hospital)	96	0.9%	49	0.6%	11	0.1%	156	0.6%
Symptoms, side effects and after effects	125	1.2%	2,000	25.3%	1,790	23.7%	3,915	15.1%
Anxiety and other mental problems	6,417	61.1%	2,940	37.3%	3,267	43.2%	12,624	48.6%
Way of living, reasons for living, set of values	465	4.4%	343	4.3%	332	4.4%	1,140	4.4%
Work and financial burdens	625	6.0%	575	7.3%	855	11.3%	2,055	7.9%
Relationships with family and other people	1,617	15.4%	748	9.5%	557	7.4%	2,922	11.3%
Total	10,501	100.0%	7,890	100.0%	7,561	100.0%	25,952	100.0%

Fig.4-2. Proportion of anxieties and burdens described during the three stages



The data obtained for each stage is shown by primary category in Table 4-1 and Figure4-2. The most prominent difference over the three stages is shown by the "anxiety and other mental problems" category, which scored 61.1% during the "around the time of diagnosis" stage, but which dropped to 37.3% in the "from diagnosis until the present time" stage and to 43.25 in the "currently" stage. On the other hand, the category entitled "symptoms, side effects, and after effects" ballooned from a mere 1.2% in the first stage to 25.3% and then 23.7 % in the subsequent stages. The anxieties that cancer patients go through vary from one period to the next, a feature that appears to be amply illustrated by this survey.

The number of pieces of data concerning the anxieties around the time of diagnosis was 10,501, from diagnosis to the present time the number was 7,890, and the number regarding current anxieties was 7,561, giving a grand total of 25,952 pieces of data. This data forms the backbone of the database of cancer-related anxieties, each of which have been allocated to one of the categories shown in Appendix 1.

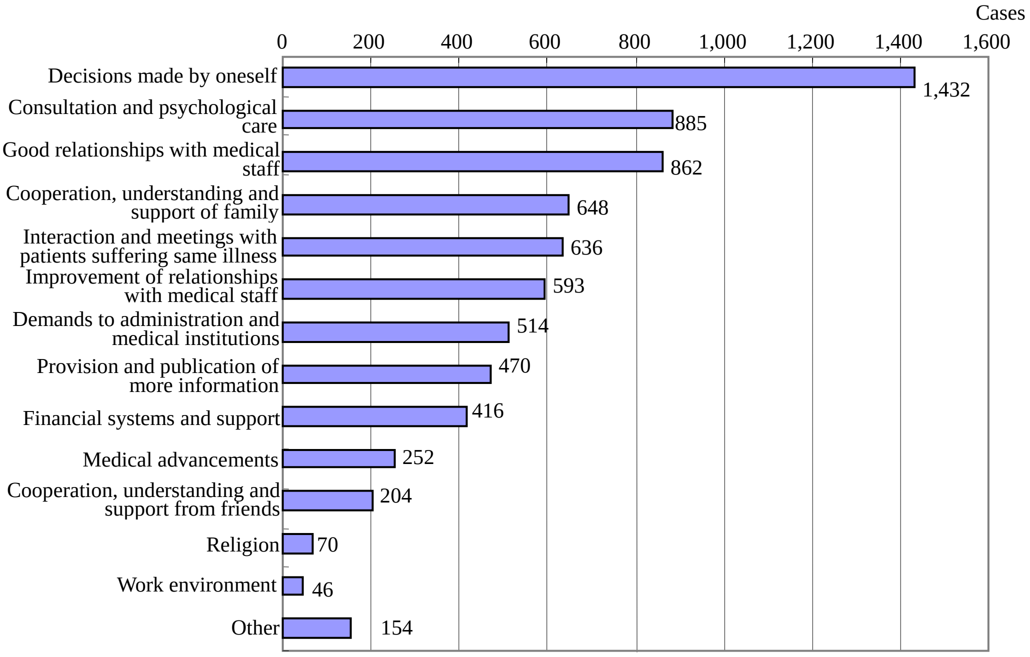
In Appendix 3, 467 examples of the 25,952 pieces of data are presented for illustrative purposes. This data can be classified and analysed in line with the various background factors enumerated in Chapter 2, such as timing of diagnosis, type of cancer, and whether or not the patient has experienced recurrence or spreading of the disease. Some of these examples will be discussed later on in the report.

5 Countermeasures, policies and tools for support regarded as essential by people who have experienced cancer

The other crucial questions in the survey asked respondents what they felt was necessary in order to alleviate their anxieties and burdens. This question elicited responses from 4,911 people. As with the analysis of the question covered in the previous chapter, we picked out some keywords from the responses and used these to sort the answers. As a result we were able to compile a total of 7,182 requests, an average of 1.5 per respondent. Question 10 on page 8 shows the answers for 14 different categories; Figure 5.1 below displays these results in descending order of frequency.

Fig. 5.1 Countermeasures, policies and support tools needed (overall results)

Number of cases=7,182



The most commonly cited need was for “decisions made by oneself”. The second most cited need was for “consultation and psychological care", closely followed by, based on the patients’ experiences, the need for a “good relationship with medical staff”. These were followed by the needs for the “cooperation, understanding and support of families”, “interaction and meetings with sufferers suffering same illness”, and “improvements of relationships with medical staff”. Respondents also expressed considerable eagerness for making “demands to administration and medical institutions”, for the "provision and publication of more information”, and for “financial mechanisms and support.” In contrast, little hope was held out for either “medical advancements” or “religion”.

A further analysis of these results reveals the following characteristics.

1. **The need for patients to resolve their situation through their own efforts was the leading result.**

Some respondents cited the importance of talking to somebody rather than suffering in silence, and the fact that there are people out there who really need the patient. Others shared pieces of individual know-how that have helped them to improve their daily lives, such as methods for preventing acid reflux in sleeping postgastrectomy patients. It is evident that it is the patients themselves who are working hardest to conquer their anxieties, even more so than the doctors and nurses treating them; also evident is the necessity for the gathering and development of various tools to support these efforts.

2. **The need for “good relationships with medical staff” was the third most cited need.**

With many respondents pointing out how important it is that relationships with medical staff are based on trust, or revealing how they were helped by a single word from their doctor, we compiled these comments under the heading of “the need for good relationships between patients and medical staff”. Elsewhere, the sixth most commonly cited need − for improvements in the relationship between patients and medical staff − displayed dissatisfaction with the current state, reflected in the comments of respondents who said that they found it difficult to discuss their problems with their doctor because he appeared to be too busy, or that they would have liked to have received some words of comfort.

3. **Many respondents related their own experiences.**

In response to the question of what respondents felt was necessary in order to alleviate their anxieties, there were a large number of responses offering concrete suggestions about consultation frameworks, aid systems and support tools for everyday life, as well as many replies based on the patients’ own experiences that stated particular areas of importance. It would appear that a very real wish on the patients’ part to relate how they resolved their anxieties is at work.

Fig. 5.2 Countermeasures, policies and support tools needed (patients' group responses)

Number of cases=964

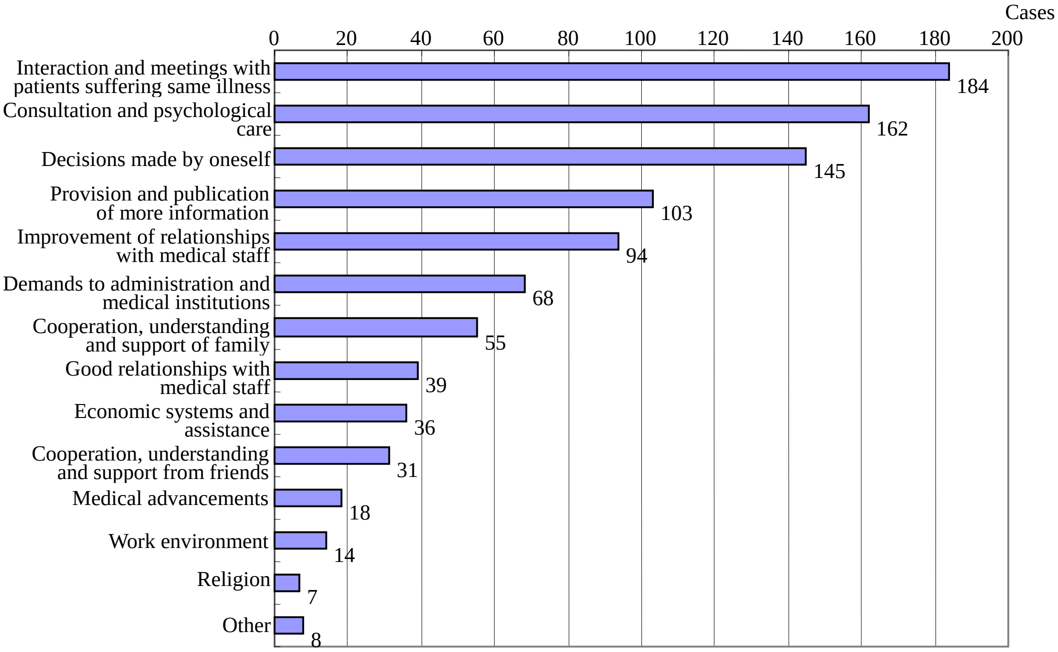


Fig. 5.2 shows the results of the free answer responses from patients' groups. Responses were received from 546 people, 964 in all, averaging 1.8 per respondent. The most commonly cited need was for "interaction and meetings with patients suffering same illness". This was followed by the need for "consultation and psychological care", the need for patients to resolve their situation through their own effort, the need for the "provision and publication of more information", and the need for an "improvement of relationship with medical staff".

The responses from patients' groups and patient support groups had the following characteristics.

1. **The need for "interaction and meetings with patients suffering same illness" was the leading response.**

Most of the respondents related how talking with other sufferers they met in hospital, and taking part in patients' groups had helped them. In particular, many people cited the following four merits of belonging to a patients' group: getting somebody to listen to them, receiving psychological support, obtaining the knowledge they needed, and sharing thoughts that "healthy" people can't appreciate.

2. **There were many concrete suggestions about the support tools needed.**

The patients’ groups and patient support groups provided many concrete suggestions about the support tools and systems needed on a day-to-day basis, no doubt because these are areas that their members have discussed together in depth.

6 Actual examples of needs cited in the area of countermeasures, policies and tools for support

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(1) Tools and support measures needed in everyday life

Tools

- Tools to aid safe and peaceful sleep in cases where the patient has to sleep on his or her back or face a particular direction (to avoid postgastrectomy acid reflux, or following a unilateral mastectomy etc.)
- Removable breasts that one can wear in the bath.
- Comfortable support undergarments (that look good and do not feel oppressive).
- Scar-covering undergarments（as a substitute for breast feeding braziers）.
- Seatbelts that do not press into scars.
- Something to protect the scars from lung cancer operations scars etc when on a crowded train (the pain is unbearable when you are being pushed up against a door).

Artificial sphincters

- I'd like to see some sort of hole to make it permeable to air, as the bag becomes full of gas.
- I'd like the inconvenience of the feces being dealt with by other people to be alleviated.

Others

- Beauty parlours for cancer patients.
- Educational and care measures to support housewives in hospital or undergoing treatment – temporary admittance to day nurseries, dispatch of helpers etc).
- A system in which the small infants of single mothers undergoing cancer treatment are looked after until the mother is well enough to do so herself.

(2) Things patients want to talk or receive advice about

About everyday life

- Eating and everyday life after discharge from hospital.
- Excretion of feces and gas（which are difficult to ask one's personal doctor about）.
- To be able to ask, until one is totally satisfied, about symptoms and everyday life (since it is sometimes difficult for women patients to ask a male doctor in great detail).

About sex

- About disruption of male functions (what will happen, and how can it be treated etc).
- Sexuality of middle-aged women (disruption of relationship with husband, feeling of guilt towards husband).

About families

- Interaction with family and people around the patients (from patients point of view).

- Interaction with the patient (from the families' point of view).）

➢ **About financial issues**

- How much will the treatment specified by the doctor actually cost?
- What scale will the financial burden reach if the disease becomes protracted?

(3) Essential information, format of the information

➢ **About treatment methods and symptoms**

- A written compilation explaining examples of symptoms at the treatment stage.
- A compilation of side effects and after effects.
- A guide to postoperative symptoms.

➢ **Based on the experiences of cancer sufferers**

- Information about how people who have had the same part of their body operated on are leading their daily lives after their operations.
- Testimonies and examples of people who have beaten cancer.

➢ **About retaining one's persona**

- How to apply cosmetics after losing hair, eyebrows, eyelashes etc.
- Information about scarves, hats, wigs etc.
- A variety of information on support undergarments.
- Information about people who have had cosmetic surgery after having their face or surrounding areas operated on.
- Information on breast reconstruction, its timing and costs.

➢ **Provision of information**

- Pamphlets detailing the in-hospital schedule and things to be careful about after discharge should be distributed to patients before they enter hospital.
- Provision of information in video format explaining what happens during the operation, rehabilitation methods, and when patients can start to eat what.
- Provision of a newsletter at medical institutions where patients are being treated (featuring information vital to patients undergoing treatment, the experiences of other patients, introductions to patients' groups and circles etc).

(4) What patients want from medical institutions

➢ **A department and systems offering continuous follow-up consultation.**

- A care division explaining to patients exactly where they stand after consultation and tests.
- An after care division responding to after effects etc.
- Comprehensive counseling by a specialist (because patients can only obtain inaccurate or fragmentary information).

- A section providing staff, other than doctors or nurses, who will look after all of a patients' needs throughout their treatment.
- A system in which some sort of simple written summary of the consultant's explanation is provided for the patient's future reference (because patients are often in a chaotic state of mind at the time of diagnosis, but are not able to find out more about their condition later on).
-

Life after being discharged from hospital

- Instruction from medical staff about preventing recurrence of the disease (advice on lifestyle, eating habits, exercise etc).
- Information and advice about lymphatic edema.
- Advice at the rehabilitation ward（some patients found the exercise they did at home was unproductive, but were able to return to work after obtaining treatment and advice from a hospital's rehabilitation ward）.
- A "recovery centre" where patients can undergo rehabilitation and prepare for social reintegration.
- Seminars that will help provide laryngectomees with the knowledge and psychological preparation required for social reintegration.
-

Facilities wanted

- A room where information can be obtained from relevant books and leaflets, and where care products can be picked up and examined at first hand.
- Pamphlet corners in waiting rooms and other easily accessible places.
- A room equipped with facilities for getting used to using an artificial sphincter (some patients found doing so unpleasant in a large room where other people could recognize them).
- A place where patients can listen to the experiences of other patients and watch videos while they wait.

Other requests

- Disclosure of information about medical institutions.
- Opening of a "patients' school" for those in the stage between diagnosis and actually going into hospital (since this is the time of the greatest anxiety).
- An explanation of the financial aid system prior to going into hospital.
- Availability of volunteers who, between them, can offer experience-based advice about every type of cancer.
- A system in which test results（photographs, cellular specimens etc）can be borrowed as the patient pleases.

(5) What is wanted of the government

System to support patients after discharge from hospital

- A home doctor system to provide continuous support after discharge from hospital.
- A consultation centre, publicly run in collaboration with local medical institutions and doctors.
- A system providing psychological and physical backing to families caring for patients.
- A round-the-clock service staff who will listen to people's anxieties.

- Lectures on vocalization for patients who have lost the ability to speak as a result of their disease.

➢ **Improvement in the general public's knowledge of cancer**

- Establishment of cancer information and consultation centres (a third party organization which would enable people who suspect they may have cancer to obtain information and counseling, and which would also provide consultation on choosing a hospital after diagnosis).

➢ **Financial mechanisms and support**

- Expanding the range of disability accreditation (to include breast cancer patients etc).
- Support for old age as contracting cancer makes it impossible to take out life insurance.
- Inclusion in insurance of the costs for support undergarments and massage treatment for lymphatic edema sufferers.
-

(6) About patients' groups and patient support group

- A nationwide patients' organization (providing information based on medical knowledge, and relaying the views of patients).
- A network of patients' groups and self-help groups.
- Provision of information on patients' groups at medical institutions (because it can take a long time to actually track down this sort of information).

7 Analysed examples of anxieties and burdens experienced

Below we present four examples, analysed from a variety of angles.

(1) Analysis by primary category

No.1 Anxiety and other mental problems（please refer to Table 4.1 on page 17）

The “anxiety and other mental problems” category accounted for 12,624 responses, 48.6% of the total, or nearly half of all the responses regarding anxieties.

The tertiary category of “anxiety over spreading or recurrence” was the most commonly cited response in the secondary “anxiety” category, with 4,033 responses. This was followed by “vague feeling of anxiety about the future”, with 3,087 responses. The latter included the microcategories of “worries about the effects of treatment and the time of treatment” (304 responses), “whether the disease would be wholly or partly cured” (438 responses), and the fact that “there may be side effects or after effects” (427 responses).

In the secondary “perception of cancer and death” category, the tertiary category of “perception of death” was the most common response, with 2,177. This included the microcategories of wondering “how long I have left to live”, “equating cancer with death”, and “fear of death”. The tertiary category of “perception of cancer” (606 responses) included the microcategories of “connecting my physical problems with cancer”, and the “anxiety of identifying oneself with sufferers of the same disease”.

In the secondary category of “varied emotions”, the most common response was the tertiary category of “mental panic and a loss of hope”, which included the microcategories of “shock (massive psychological impact, feeling as if one’s mind has gone completely blank)”, feelings of “why me?“, “fear”, “loss of hope/breakdown” (“it’s the end”, “the treatment won’t work”, “the future is pitch black”), and “insomnia/inability to eat properly” caused by the shock. A further 561 responses cited the tertiary category of “continuous psychological anxiety”, describing prolonged periods of unrelieved panic.

Analysing the primary category of “anxiety and other mental problems” in terms of the three temporal stages reveals that the spread of the responses was: 6,417 “around the time of diagnosis”, 2,940 “from diagnosis to the present time”, and 3,267 “currently”. Anxiety and other mental problems are the leading response at all stages, but the number does decline in the two later stages.

The table showing the “Top 20 anxieties and burdens in the tertiary category”, which form Appendix 2, is a look at the temporal changes by tertiary category. These anxieties changed over time. During the stage “around the time of diagnosis”, uncertainties surrounding the negative associations with the word “cancer” and subsequent fears such as “what’s going to happen to me?” as well as uncertainties about the future were dominant (tertiary categories such as a “vague feeling of uncertainty about the future”, “mental panic and a loss of hope”, and “perception of death” etc). Anxieties that were reduced over the three stages were: “a vague feeling of uncertainty about the future” (1,915 to 603 to 569 responses); “mental panic/loss of hope” (1,736 to 300 to 80 responses), and “perception of death” (1,674 to 287 to 216 responses). On the other hand, “anxiety over spreading or recurrence”, which was the fourth highest response during the stage “around time of diagnosis”, rises to first place by the next two stages (from 663 to 1,304 to 2,066 responses).

The tertiary category of a “continuous psychological anxiety”, which fell from 249 to 196 to 116 responses across the three stages, included the microcategories of “depression”, “always feeling insecure”, “loss of will”, and “inability to control emotions”; whilst the number of these responses is small, they indicate that a certain proportion of cancer patients endure psychological instability throughout all the stages.

No.2 Symptoms, side effects and after effects（please refer to Table 4.1 on page 17）

This primary category accounted for 15.1%, with 3,915 responses.

The wide variety of anxieties voiced differed according to therapy type (anticancer drug therapy, surgery, radiotherapy) and the organ affected. These anxieties are not entirely limited to the symptoms or after effects themselves, but in many cases include concern about how these will affect the patient’s everyday life (eating, excretion, sleep, housework etc) as well as their sex lives.

This in turn leads to symptoms and after effects becoming a major source of stress. In many cases patients’ mental health and social life are affected as they become reluctant to trouble the people around them and eventually cease to go outdoors, thus losing touch with their friends and neighbours.

No.3 Relationships with family and other people（please refer to Table 4.1 on page 17）

This primary category accounted for 11.3% of responses, with a total of 2,922.

The secondary category of “relationships with family” (2,358 responses) contains the tertiary categories of “concern about children” (470), and “relationships with children” (240), and the microcategories of “worrying that the disease will be passed on to my children”, “unable to take care of children properly”, and the “effect on physical or mental health of children” — anxieties about parental roles and feelings. The tertiary category of “relationships with spouse” displays the patients’ feelings towards their partner in the microcategories of “leaving my spouse widowed”, “worrying about aged and sick spouse”, “worrying about spouse’s future”, and “feeling sorry about my spouse”. On the other hand, the tertiary category of “problems pertaining to relationship with spouse” (189 responses), includes microcategories reflecting practical problems such as “both partners contracting an illness at the same time”, and sources of “conflict between husband and wife such as sexual relationships”, “not gaining enough support from the key figure in my life”, and a “lack of understanding on the part of my spouse”.

No.4 Work and the financial burdens（please refer to Table 4.1 on page 17）

The 2,055 responses concerning the primary category of “work and financial burdens” accounted for 7.9% of the overall total.

In the secondary category of “financial problems”, the tertiary categories of “medical expenses” (506 responses) was the most commonly cited, followed by “financial anxieties about one’s future livelihood” (255 responses).

In the secondary category of “problems concerning work”, the tertiary categories of “anxieties about going back to work or continuing work” (575 responses), and “the impact of cancer on work” (336 responses) were the most commonly cited. Though there were only 32 such responses, “anxieties about being fired” were also evident. And whilst it is not directly connected to work, the tertiary category dealing with the fear that cancer may not be properly understood at one’s workplace elicited 60 responses.

No. 5 Way of living, reasons for living and set of values（please refer to Table 4.1 on page 17）

The 1,140 responses regarding the primary category of “way of living, reasons for living and set of values” accounted for 4.4% of the overall total.

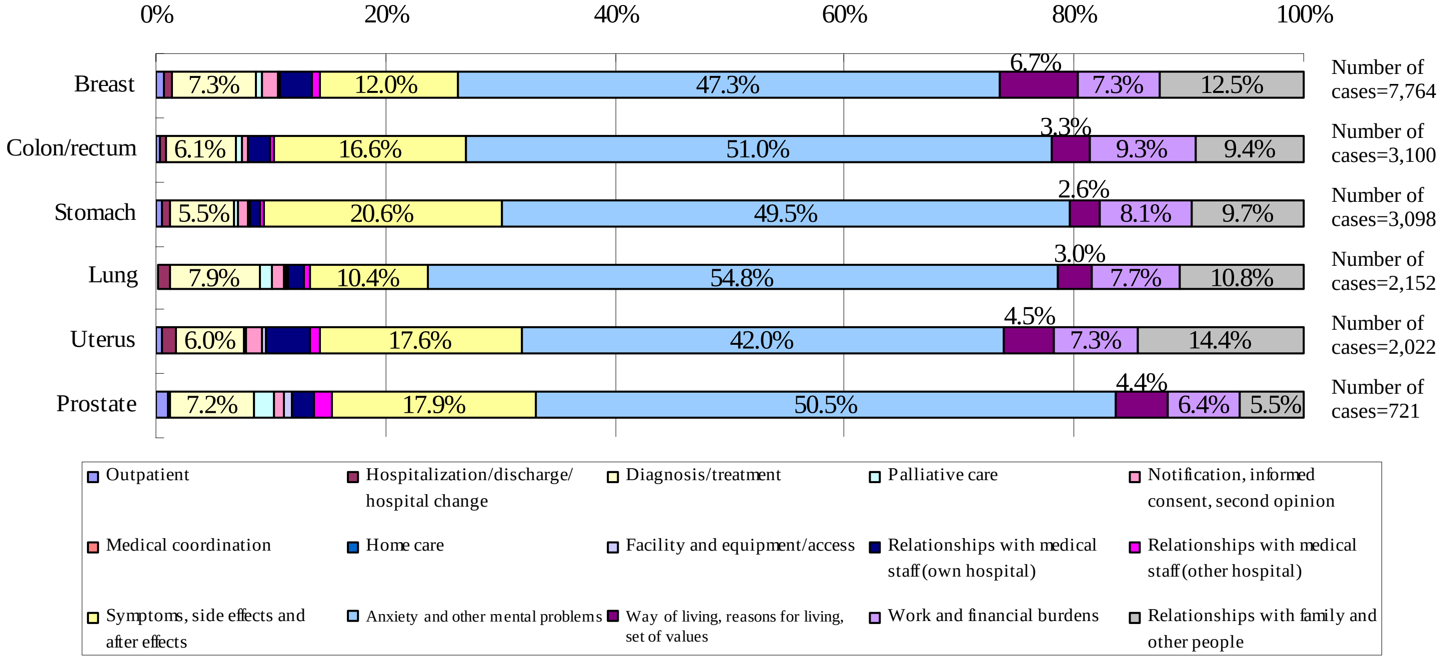
The tertiary category of “approach to life after having suffered from cancer” (360 responses), within the secondary category of “way of living”, showed patients anxieties and doubts about their lifestyles and how they should lead their lives in the future.

The secondary category of “self-identity” contains tertiary categories reflecting the trauma of “external physical changes” (380 responses), anxieties surrounding whether patients’ will be able to carry on with their sexuality (“awareness and changes in awareness of one’s own femininity or masculinity”, 116 responses), and 75 responses citing anxiety over “changes in one’s own awareness of self”.

(2) Analysis by type of cancer

The most commonly affected parts of the body in this survey were, in order of the number of respondents: breast (1,904), colon/rectum (1,055), stomach (1,046), lung (749), uterus (498), prostate gland (302). Figure 7.1 below shows the anxieties of the respondents with these commonly occurring cancers.

Fig. 7.1 Responses on anxieties by type of cancer



Regardless of the type of cancer, the most commonly cited response was “anxiety and other mental problems”, followed by anxieties about “symptoms, side effects and after effects”.

Whilst the primary category of “anxiety and other mental problems” shares many common features throughout all the types of cancer, the question of “symptoms, side effects and after effects” displays subtle variations form one disease to another. To illustrate these variations, we compiled Table 7.1, in which the microcategories included in the primary category of “symptoms, side effects and after effects” are presented in order of occurrence.

Tab. 7.1 Top 10 microcategories of the anxieties related to “symptoms, side effects and after effects” by type of cancer

	Breast	Colon/Rectum	Stomach	Lung	Uterus	Prostate
1	Hair-loss caused by anticancer drugs	Diarrhea, frequent stools, fecal incontinence	Inability to eat enough after gastrotomy	Loss or return of strength post treatment	Swelling from lymphedema	Loss of bladder control
2	Other symptoms caused by anticancer drugs (anemia etc)	Constipation	Weight loss/inability to gain weight after gastrotomy	Continuous post-operative after-effects (pain, sore shoulders)	Hair loss caused by anticancer drugs	Increased urinary frequency
3	Continuous post-operative after-effects (pain, sore shoulders)	Loss or return of strength post treatment	Loss and return of strength post treatment	Other continuous post-operative after-effects	Physical and psychological unease in every-day life (lymphedema)	Sexual dysfunction such as impotence or loss of sexual appetite
4	Swelling from lymphedema	Irritation of frequent visits to the toilet when outside or at work due to dyschezia	Other effects on food-intake due to gastrotomy	Hair loss caused by anticancer drugs	Other symptoms due to side-effects of radiation	Other continuous after effects
5	Other continuous post-operative after effects	Handling of artificial anus	Diarrhea, frequent stools, fecal incontinence	Pain (continuous symptoms)	Loss of bladder control	Sleep loss due to urination problems
6	Nausea caused by anticancer drugs	Whether or not health will return to same level as before illness	Dumping after meals because of gastrotomy	Other continuous symptoms	Menopausal symptoms due to organ removal etc (hormone balance disrupted)	Weight gain caused by hormone treatment etc
7	Loss or return of strength post treatment	Other symptoms caused by anticancer drugs (anemia etc)	Recovery after surgery	Other symptoms caused by anticancer drugs (anemia etc)	Loss and return of strength post treatment	Loss or return of strength post treatment
8	Menopausal symptoms due to organ removal etc (hormone balance disrupted)	Continuous post-operative after-effects (pain, sore shoulders)	Food gets stuck because of gastrotomy	Nausea caused by anticancer drugs	Nausea caused by anticancer drugs	Constipation
9	Pain (continuous symptoms)	Other continuous post-operative after-effects	Constipation	Dizziness and shortness of breath when walking	Other symptoms caused by anticancer drugs (anemia etc)	Whether or not health will return to same level as before illness
10	Whether or not health will return to same level as before illness	Other continuous symptoms	Every-day concerns due to gastrotomy	Shortness of breath when moving	Other continuous post-operative after-effects	Other symptoms caused by anticancer drugs (anemia etc)

In the case of breast cancers, the side effects of anticancer drugs, and lymphedema were the major concerns. Colon/rectum cancer sufferers cited constipation, loss of physical strength, and a colostomy as their prominent fears. Those with stomach cancer were mainly concerned with postgastrectomy after effects and loss of physical strength. Lung cancer patients, due perhaps to the high recurrence level of the disease, were particularly anxious about the after effects of surgery, loss of physical strength, and the side effects of anticancer drugs. Uterus cancer sufferers expressed fears about lymphedema, the side effects of anticancer drugs and radiotherapy, the after effects of surgery, and incontinence. Prostrate cancer patients' main concerns were postoperative urination problems, problems about their sex lives, and the side effects of hormone treatment.

Thus it can be seen that the anxieties about "symptoms, side effects and after effects" differ widely depending on the type of cancer. This database of patients' anxieties analyses the worries about every type of cancer, all of which will prove to be an invaluable source of information in the search for countermeasures.

The following is a compilation of the results of a further analysis of the anxieties and the characteristics that were made apparent by the analysis.

1 Breast cancer (1,904 respondents, 7,764 responses)

Amongst the leading secondary category of "anxiety", within the leading primary category of "anxieties and other mental problems", the tertiary category of "anxiety over spreading or recurrence" accounted for 1,266 responses across the three time stages, 16.4% of the total. The number or responses increased across the stages, from 227 to 409 to 630.

The leading secondary category, the "side effects of treatment" (within the second-highest scoring primary category of "symptoms, side effects and after effects") included these tertiary categories: the "symptoms of side effects of anticancer drugs" such as hair loss; "other after effects of surgery" such as pain, stiff shoulders and an inability to raise one' arms; "after effects of irradiation therapy" such as skin damage.

The third-highest scoring primary category, "relationships with family and other people", accounted for 12.5% of the breast cancer patients' responses (969 responses). The tertiary categories covering "concern about children", "relationships with family", and "relationships with children" are the most commonly cited in the secondary category of relationships with family. This suggests a tendency for mothers to become worried about their role and feelings as both a mother and as a housewife.

2 Colon/Rectum cancer（1.055 respondents, 3,100 responses）

The second-highest scoring primary category of "symptoms, side effects and after effects", elicited 516 responses, and accounted for 16.6% of the total. The most commonly cited anxieties were, in order of occurrence, “symptoms arising from dyschezia” such as constipation, diarrhea or frequent stools (109 responses), fears about the “symptoms of side effects of anticancer drugs”, such as nausea (53 responses), and “impact of a colostomy on daily life”, such as restricted movement (44 responses). It should be noted that the extent and method of the surgery performed on intestinal and rectum cancer patients varies according to the location of the cancer and its degree of progression; in some cases therapy combining chemotherapy and irradiation therapy is carried out (therapy also used to treat other parts of the body), and the symptoms displayed by patients undergoing such treatment are varied in their nature and extent.

Furthermore, whilst progress is being made in the study of surgical techniques for preserving bodily functions and maintaining the patient’s quality of life, anxieties and burdens such as dyschezia following surgery regardless of whether an colostomy has been inserted or not, the side effects of anticancer drug treatment, vary according to the type of therapy used. Dyschezia or the insertion of an colostomy affects not just the patients’ symptoms and treatment, but also their everyday lives. The tertiary category covering the effects of “impact of dyschezia on daily life”, which elicited 35 responses, contained microcategories that showed the presence of such anxieties: the “irritation of frequent visits to the toilet when outside or at work”; “soiling of undergarments because of dyschezia”; the “need to be careful in front of other people due to dyschezia”; the “insufficient sleep due to need to visit the toilet frequently”, and the “inability to go outdoors due to excessive defecation”.

3 Stomach cancer (1,046 respondents, 3,098 responses)

The second largest primary category of “symptoms, side effects and after effects” accounted for 639 responses, or 20.6% of the stomach cancer patients’ anxieties. In order of frequency, the most commonly cited anxieties were the tertiary categories of the “impact of a gastrotomy on eating”, such as the inability to eat adequately (203 responses), after the “impact of a gastrotomy” such as the inability to put weight on (98 responses), and matters surrounding “life and health management after treatment”, such as loss of physical strength.

In order not to degrade their quality of life, every effort is made to provide patients with treatment that places a minimal burden on their body, such as endoscopic removal or the examination of other surgical methods. Depending on the state of the disease, however, in some cases a gastrectomy is unavoidable. It is clear that most of the people who have undergone a gastrectomy harbour anxieties about eating, weight loss, and loss of physical strength.

4 Lung cancer (749 respondents, 2,152 responses)

The primary category of “anxiety and other mental problems” accounted for 54.8% of the lung cancer suffers’ worries, eliciting 1,180 responses — the highest proportion of any of the organs dealt with in this chapter. The secondary category of “perception of cancer and death” contained a number of microcategories such as “wondering how long I have left to live”, “equating cancer with death”, “connecting my physical problems with cancer”, and “anxiety of identifying oneself with sufferers of the same disease.” The secondary category of “varied emotions” contained microcategories citing problems such as a “personal lack of confidence in the efficacy of the treatment”, “depression”, “anxiety due to lack of knowledge”, and “always feeling insecure.”

5 Uterus cancer (498 respondents, 2,022 responses)

Looking at the tertiary categories in the second largest primary category of “symptoms, side effects and after effects,” anxieties about lymphedema and urination problems are predominant. Lymphedema often occurs after a patient has been given irradiation therapy. Associated tertiary categories included “Symptoms arising from lymphedema” such as swelling, tightness, and lethargy, as well as the “impact of lymphedema on daily life”, such as difficulties in going out, working and housework, and restrictions in the range of clothes that sufferers can wear. The tertiary category of the “impact of lymphedema on daily life” included many cases in which this condition itself induced emotional disturbances such as denial, distress, and negative thinking. The tertiary category of “symptoms arising from urination problems” also included the microcategory of “loss of bladder control”.

The third largest primary category, “relationships with family and other people”, accounted for 14.4&% of the uterine patients’ anxieties, with 292 responses. 247 of these were in the secondary category of “relationships with family”. As was the case with the breast cancer patients, there is a tendency for patients to be anxious about their role within the family as a mother. At the same time, a number of anxieties concerning relationships between patient and spouse, including the microcategories of “feeling sorry about my spouse”, “sexual relationships”, “not gaining enough support from the key figure in my life”, and a “lack of understanding on the part of my spouse”.

6 Prostate cancer (302 respondents, 721 responses)

The second largest primary category, “symptoms, side effects and after effects”, accounted for 129 responses, 17.9% of the total for prostate cancer. Within the tertiary category of “symptoms arising from urination problems” (43 responses), excessive urination and incontinence were cited; within the tertiary category of “symptoms caused by changes in hormonal balance” (11 responses), weight gain profuse sweating and hot flushes due to hormone therapy were cited; and inability to have sexual intercourse, loss of sexual appetite, and inability to ejaculate were cited in the eight responses in the tertiary category of “symptoms arising from sexual dysfunction”.

In the primary category dealing with “way of living, reasons for living and set of values” (32 responses), the secondary category of “self-identity” (10 responses) contained the microcategories of “anxieties about self-identity and ability to maintain masculine sexuality”, and “changes or loss of masculine sexuality”, though the actual number of these responses was small.

(3) Whether the disease will recur or spread

Fig 7.2 Number of responses about anxieties concerning whether the disease will recur or spread (aggregate for the three stages)

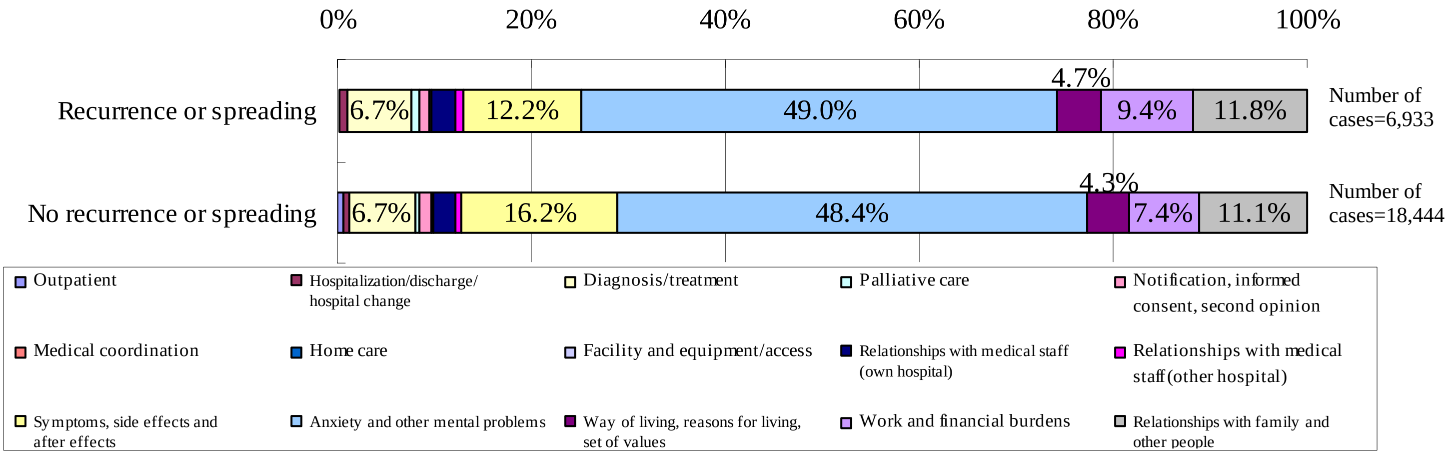
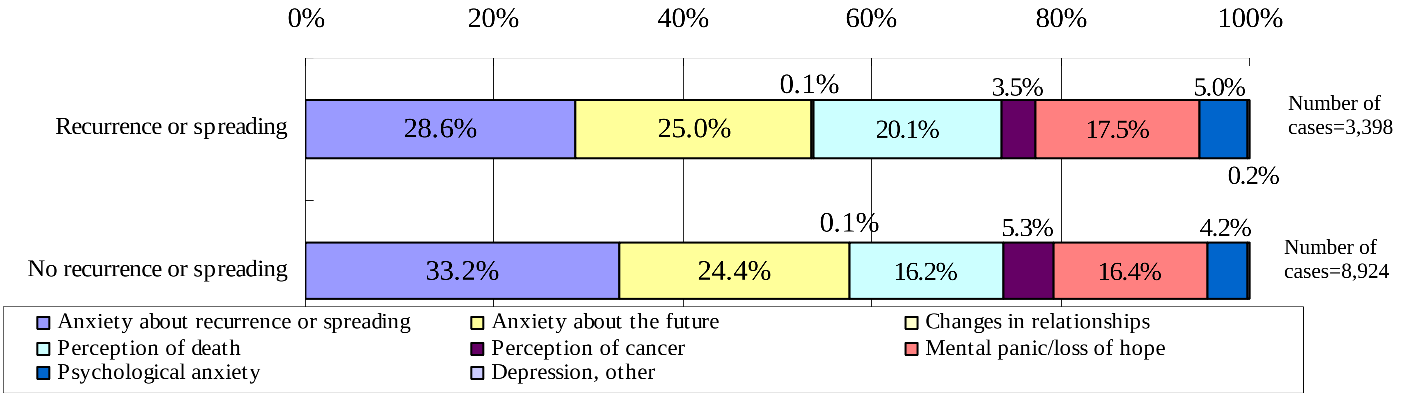


Figure 7.2 shows the main categories of anxieties for the 1,852 people who had experienced recurrence or spreading of cancer (6,933 responses), and the 5,744 people who had not (18,444 responses). The primary category of “anxiety and other mental problems” was cited by roughly the same proportion of those who have experienced recurrence or spreading (49%) and those who have not (48.4%).

Fig. 7.3 Anxiety and other problems caused by recurrence or spreading (aggregate across the three stages)



As can be seen in Fig. 7.3, which shows the details of the primary category of 2anxiety and other mental problems” broken down into secondary categories, there is not a great deal of difference in the anxieties of either group. Both groups cited the tertiary category of “anxiety over spreading or recurrence” as their major worry. As the data for the “no recurrence or spreading” group contains many instances of patients who have just completed their treatment, it is not surprising that a large number of them are “anxious about spreading or recurrence”.

Fig. 7.4 Anxiety and other mental problems by the number of years elapsed without any recurrence or spreading (as of present time)

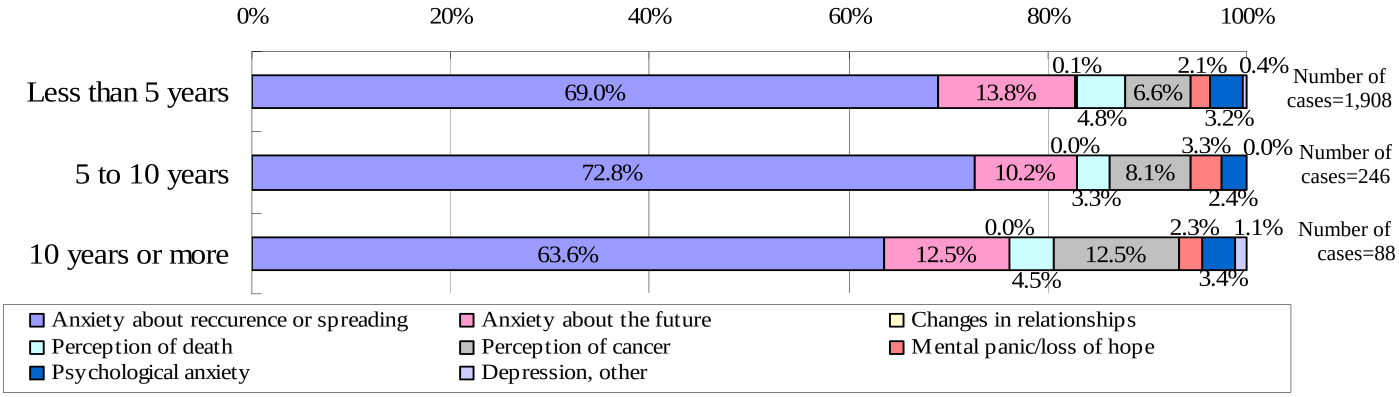


Figure 7.4 shows the responses for the "currently" time stage of the "no recurrence or spreading" group, by the number of years that have elapsed since they were diagnosed. The figures for the tertiary category of "anxiety over spreading or recurrence" were largely unchanged regardless of whether the respondents had experienced cancer for five years or less, for between five to ten years, or for ten years or more. Even cancer patients who have not experienced recurrence or spreading after five to ten years, and who can therefore clinically speaking be regarded as cured, live their daily lives with the same degree of anxiety about further cancer as those whose diagnosis was less than five years ago. One reason for this may be that the doctors of these patients have not correctly informed them that if they experience no further recurrence or spreading after five years then there is a good likelihood that they are cured. This suggests that inadequate provision of information to patients leads to unnecessary anxieties.

4 Analysis by gender

Of the 7,837 valid respondents 3,531 were men, and 4,220 women. 873 men and 606 women chose not to complete the free answer section. The number of responses derived using the classification totaled 9,583 from men, and 16,074 from women. The average number of responses per person was 3.6 for men, and 4.4 for women. It was women the women respondents who related the most anxieties.

Fig 7.5 Number of responses about anxieties and burdens by gender

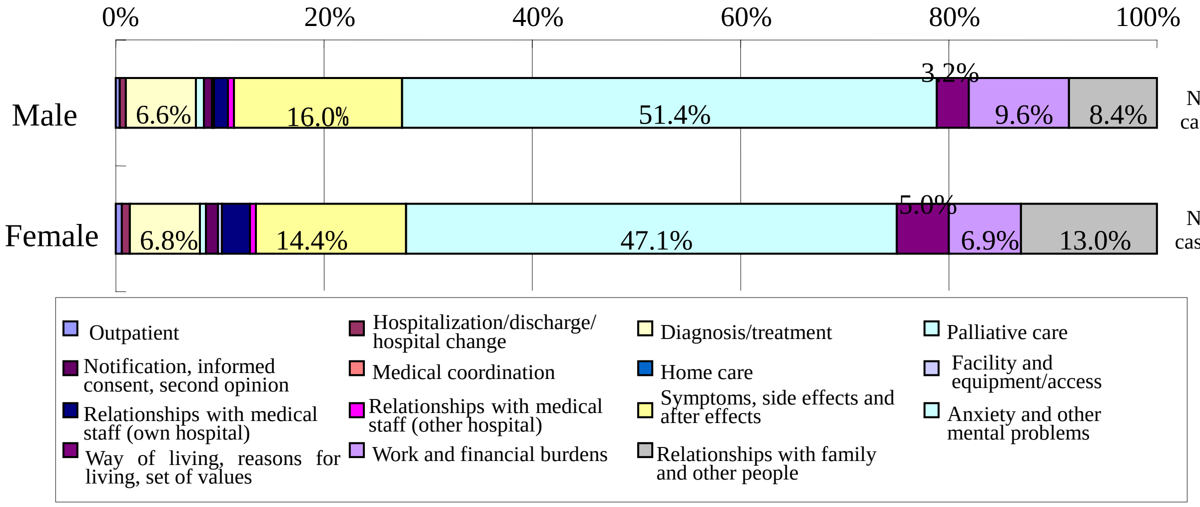


Figure 7.5 shows the state of patients' anxieties and burdens by gender. A look at the situation reveals the following characteristics.

1 The "anxiety and other mental problems" category is the most frequently cited, accounting for around half of the responses from both men and women

4,923 of the responses from men, and 7,572 of the responses from women concerned the primary category of "anxiety and other mental problems", approximately 50% of all the responses.

2 Women were more anxious about "relationships with family and other people"

More women provided responses in the primary category of anxieties about "relationships with family and other people". This is shown by the fact that in the secondary category of "relationships with family", 1.6% of the responses concerning the two headings concerning husband-wife relationship were from men, and 2.2% from women, and whilst 1.0% of the responses concerning the two headings dealing with children were from male respondents, 3.8% were from women.

3 More women are anxious about "self-identity"

In the primary category dealing with "way of living, reasons for living and set of values", the responses in the secondary category of "self-identity" (38 responses/0.4% from men, 518 responses/3.2% from women) illustrates that this is a matter that more women tend to worry about. They are concerned about changes in their appearance and their femininity.

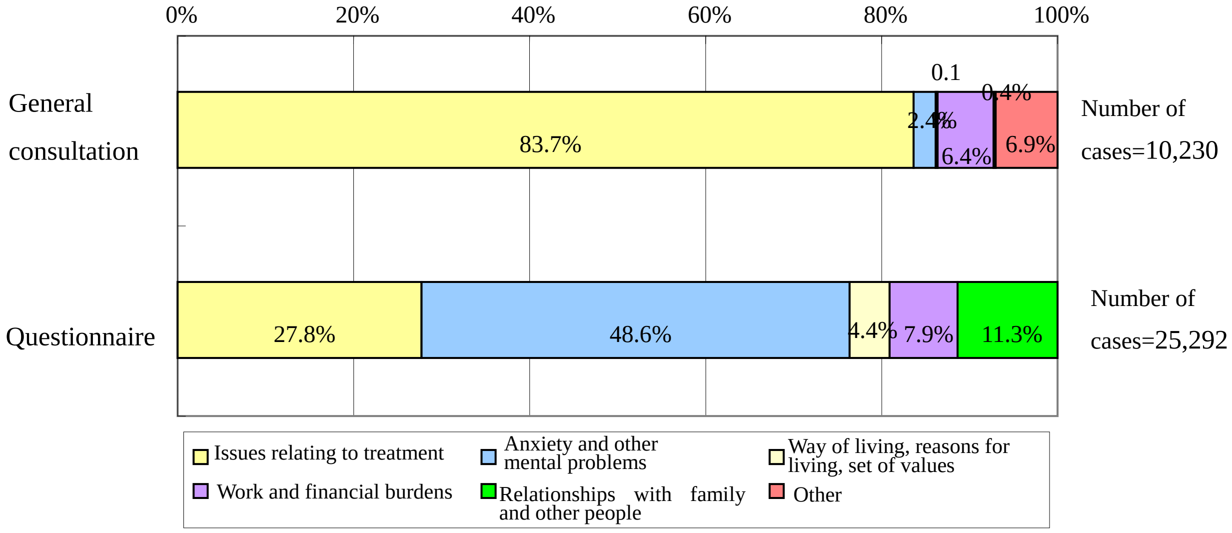
8 A comparison of the details of general consultation with the results of the questionnaire

A total of 10,230 consultations took place at Shizuoka Cancer Center’s general consultation service between September 2002 and December 2003. Below is a comparison of the details of these consultations with the results of the questionnaire, using the same categorization as employed in this survey.

Table 8.1 Comparison of the details of general consultation with the results of the questionnaire

		General consultation		Questionnaire	
	Primary category	(Number of cases)	(%)	(Number of cases)	(%)
Matters concerning medical care	Outpatient	2,548	24.9%	121	0.5%
	Hospitalization/discharge/ hospital change	530	5.2%	195	0.8%
	Diagnosis/treatment	2,053	20.1%	1,738	6.7%
	Palliative care	243	2.4%	158	0.6%
	Notification, informed consent, second opinion	2,262	22.1%	291	1.1%
	Medical coordination	42	0.4%	2	0.0%
	Home care	141	1.4%	3	0.0%
	Facility and equipment/access	250	2.4%	52	0.2%
	Relationships with medical staff (own hospital)	83	0.8%	580	2.2%
	Relationships with medical staff (other hospital)	97	0.9%	156	0.6%
	Symptoms, side effects and after effects	313	3.1%	3,915	15.1%
	(subtotal)	**8,562**	**83.7%**	**7,211**	**27.8%**
Matters not concerning medical care	Anxiety and other mental problems	246	2.4%	12,624	48.6%
	Way of living, reasons for living, set of values	15	0.1%	1,140	4.4%
	Work and financial burdens	651	6.4%	2,055	7.9%
	Relationships with family and other people	46	0.4%	2,922	11.3%
	(subtotal)	958	9.4%	18,741	72.2%
	Other	710	6.9%	0	0.0%
	Total	10,230	100.0%	25,952	100.0%

Fig. 8.1 Comparison of the details of general consultation with the results of the questionnaire



For the sake of convenience, the primary categories from outpatient matters through to symptoms, side effects and after effects have been combined into the single category of "matters concerning medical care" in Figure 8.1. Details relating to general consultation that do not fit into the questionnaire's classification table have been added to the "other" category. The characteristics that may be discerned from Table 8.1 are as follows.

1 Matters concerning medical care are discussed in general consultation

Outpatient matters, hospitalization and discharge, diagnosis and treatment, disclosure, informed consent, and other matters relating to medical care account for 83.7% of the contents of general consultation. Anxieties about which the patients judge they will be able to elicit a relatively clear response to are being discussed.

2 Cancer patients have two sorts of anxieties: the sort they want to discuss, and the sort that they do not want to discuss.

It appears that cancer patients have two sorts of anxieties. The first type is anxieties that are easily discussed, such as those concerning medical care. For better or worse, most of the matters concerning medical care reach a conclusion as time goes by. The matters that patients are discussing in general consultation are anxieties that they have come up against during medical care, and which they think can be solved in some way. Since little can be done about anxieties concerning "symptoms, side effects and after effects", even if they are discussed as part of the medical care process, this subject is also covered in detail in the questionnaire.

The second type of concerns — deeply rooted “anxiety and other mental problems”, questions of “way of living, reasons for living and set of values”, and “relationships with family and other people” — include many issues not readily solved; they are a constant feature of the questionnaire, in which they account for a large proportion of the responses, but they are not often discussed in general consultation.

9 Some vital messages

The following is a compilation of messages, based on the results of the survey, which will be of use to cancer patients, their families, people in the medical profession, and social and medical institutions. Looking towards the future, there is a need for messages aimed at each type of cancer.

To patients and their families

- ☞ **All cancer patients are faced with serious and varied anxieties and burdens. The majority of cancer patients meet these anxieties head on, and do the best that they can to deal with them.**
- ☞ **Learning about other sufferers' experiences can help patients to prepare themselves mentally.**
- ☞ **Some anxieties can be dissipated through the provision of accurate information. (Such as worrying about recurrence or spreading despite having been cured.) It's better to talk to someone than suffer alone in silence.**
- ☞ **Families should understand that people who have suffered from cancer continue to nurse anxieties for years after they have recovered.**

To the medical staff

- ☞ **From notification to subsequent treatment to observation, the types of anxieties that patients experience vary from stage to stage.**
- ☞ **There are two types of anxiety: the "type patients want to talk about", and the "type they don't want to discuss". Be aware that there are things some patients don't want to talk about.**
- ☞ **Even though patients may appear to be in good spirits when they visit hospital, they are still harbouring anxieties. Asking people if they are worried about anything is an important step in good communications.**
- ☞ **Patients who are probably cured should be clearly told so, thus preventing further "anxiety about recurrence and spreading".**
- ☞ **Many patients suffer anxieties peculiar to the "symptoms, side effects or after effects" of their particular cancer. Treatment should be given to reduce and alleviate these where possible.**

- ☞ **Be aware of the huge impact on eating habits, excretion and so on of "symptoms, side effects or after effects", listen to the patients' anxieties, and try to provide appropriate care.**

- ☞ **Cancer patients are hoping for an improvement in their relationships with medical specialists.**

- ☞ **Whilst the majority of cancer patients are grateful for their family's support, some patients suffer from unsupportive families.**

- ☞ **Cancer patients realize the importance of their own efforts to help themselves in overcoming their anxieties. It is vital that this is supported.**

To social and medical institutions

- ☞ **The development of a system for medical consultation and psychological care is necessary.**

- ☞ **Departments dealing with after effects are needed.**

- ☞ **Psychological and physical care for families looking after patients is needed.**

- ☞ **Providing information about cancer treatment helps to alleviate anxieties.**

- ☞ **Provision of information about financial support mechanisms is important.**

- ☞ **When treatment is continued and prolonged after patients have left hospital, the financial and social stresses relating to medical expenses and work become bigger.**

- ☞ **Since most cancer patients are elderly and live off pensions, their income is small.**

- ☞ **Some patients have to retire or close down their businesses because of cancer. Though they are few in number, some people are also suffering the anxiety of having been made redundant.**

- ☞ **Meeting sufferers of the same disease and taking part in patients' groups are useful ways of reducing anxieties.**

10 Strategies for the future

This report was compiled with an emphasis on making it accessible to the widest possible audience. We will continue to compile the results using the following methods, and use them to develop projects that will be useful in improving cancer patients' quality of life.

1 Database of patients' anxieties

The twenty thousand or so responses about cancer patients' anxieties and burdens in the free answer section have been put into electronic format; after grouping these according to content, they will be put into a few lines of text as shown in Appendix 3, and the analysis of them will completed in the form of a simple database.

2 Database of anxieties by type of cancer, based on the original database

Whilst there are similarities in the anxieties and burdens experienced by those who have gone through the disease of cancer, there are also considerable variations according to the type of cancer, as the second part of Chapter 7 of this report shows (Analysis by type of cancer, page 31). We will use the common anxieties for each type of cancer in the database to create a secondary database of anxieties classified by type of cancer.

This will help patients and their families to see what sort of anxieties people with the same type of cancer have experienced. Asked about countermeasures, policies and tools or support, many patients said they wanted to benefit from the experiences and advice f patients with the same type of cancer. It is clear that providing detailed accounts of how previous sufferers fought their disease is of the utmost importance. The type-specific database will also help doctors to improve their communication with patients and provide them with better care, and will thus be extremely helpful to medical staff in all hospital departments.

3 Comparison with the general consultation database

By analysing the divergences between the database of patients' anxieties and the ongoing general consultation database created at Shizuoka Cancer Center, we will gain an understanding of the anxieties that patients discuss at medical institutions, and the anxieties they do not talk about, which were made apparent in the questionnaire. We will use this to provide the psychological care that patients want.

4 Production and publication of a Q&A collection about cancer-related anxieties

Based on the database of patients' anxieties, the medical profession, patients and patients' support groups, government and others, will work together to find concrete ways of solving these anxieties, and compile a collection of questions and answers containing remedial measures for each anxiety. This will be published in pamphlet form, and made available over the Internet. It will help to alleviate the sense of isolation endured by those facing up to cancer, and reduce their anxieties.

5 Gaining the understanding of society

These databases will be widely publicized and put to use in making society as a whole appreciate the anxieties and burdens faced by cancer patients and their families. The databases will also be used as a keystone for improving systems to support cancer patients and the development of new medical equipment and software. Finally, we will do our best to reverse the erroneous impression that cancer is an “incurable disease”.

The Research team

The study group for "Research into Better Medical Consultation and Psychological Care for Mainly Short-term (less than 5 years after treatment) Cancer Survivors", part of the clinical research project to establish effective medical techniques, conducted under health and labour sciences research grants from the Ministry of Health, Labour and Welfare (MHLW).

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Cooperating Groups	Akebonokai Shizuoka Chapter
	Izu Friends of Urinary Disorder Patients

Cooperating Groups

Idea Four

The Listening Patients’ Network “VOL-Net”
The Support Group “α”
Uterus/Ovarian Cancer Support Group “Group aiai”
Japan Ostomy Association, Inc. Shizuoka Chapter
Tukiji-kai
Tsutsujinokai
Dongurinokai
Nozominokai Shizuoka Chapter
Institute of Hospice Care
Hohoeminokai
Lymphedema Society
Lymphedema Support Group “Asunaro-kai”
B-8 Friendship Society
Japanese Society of HCRM (Health Care Relationship Marketing)
Gynecologic Cancer Support Group “Orange Tea”
Rakkan Net
Peer

The study group for “Research into Societal Attitudes towards Cancer Survivors”, supported by a Grant-in-Aid for Cancer Research from the MHLW

Number 11-20

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The study group for “Research into the Improvement of Cancer Treatment in Japan”,
supported by a Grant-in-Aid for Cancer Research from the MHLW
Designated research number 13-3

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Appendix 1: Cancer anxieties database (classified table)

Primary category	Secondary category	Tertiary category	Microcategory
1 Outpatient	1 - 1 Outpatient	1 - 1 - 1 Procedures for outpatient	
		1 - 1 - 2 Outpatient treatment	1 - 1 - 2 - 1 Waiting times are too long
			1 - 1 - 2 - 4 Difficult to deal with undergoing anticancer treatment as an outpatient
	1 - 2 Choice of hospitals and physicians	1 - 2 - 1 Choice of hospital	1 - 2 - 1 - 1 Difficult to obtain information on how to choose a hospital
			1 - 2 - 1 - 2 Difficult to decide upon department to go to for treatment
			1 - 2 - 1 - 3 Criteria for choosing of hospitals (transportation, facilities, etc.)
			1 - 2 - 1 - 4 Choice of hospital to go to for cancer treatment
			1 - 2 - 1 - 5 Difficult to choose hospital capable of dealing with
			1 - 2 - 1 - 6 Unable to find a hospital which will perform a bone marrow transplant
		1 - 2 - 2 Choice of doctor	1 - 2 - 2 - 1 Worried about being able to find a doctor I can trust
2 Hospitalization/discharge/ hospital change	2 - 1 Hospitalization	2 - 1 - 1 Admittance procedures and preparing for admission	2 - 1 - 1 - 1 Insufficient explanation about undergoing inpatient treatment
		2 - 1 - 2 Prior to hospitalization	2 - 1 - 2 - 1 Long wait for admission
			2 - 1 - 2 - 2 Difficult to deal with daily life while waiting for admission (unable to seek help from others)
			2 - 1 - 2 - 3 Concerned that my condition might become worse while waiting for admission
			2 - 1 - 2 - 4 Concerned because of my lack of knowledge about changes in my condition or the progress of the disease while waiting for
		2 - 1 - 3 Feelings regarding	2 - 1 - 3 - 1 Concerned about being hospitalized
			2 - 1 - 3 - 2 Concerned about stress during hospitalization
			2 - 1 - 3 - 3 Concerned about my actions, words, and behavior towards
			2 - 1 - 3 - 4 Impoliteness towards other people (nurses, other patients, etc.) during my hospitalization
			2 - 1 - 3 - 5 Repeated hospitalizations
	2 - 2 Discharge	2 - 2 - 1 Preparation for discharge	
		2 - 2 - 2 Discharge from hospital	2 - 2 - 2 - 1 Possibility of discharge
			2 - 2 - 2 - 2 Surprisingly quick or long time until discharge
			2 - 2 - 2 - 3 Forced to leave hospital because of changes in systems of treatment
	2 - 3 Hospital change	2 - 3 - 1 Feelings regarding transfer to another hospital	2 - 3 - 1 - 1 Worried about whether I should switch to another hospital
			2 - 3 - 1 - 2 Concerned about what sort of person my new doctor would be if I switched hospitals
			2 - 3 - 1 - 3 Concerned about level of medical treatment at new hospital
			2 - 3 - 1 - 4 Would like to switch hospitals but find it difficult to say so to my present doctor
		2 - 3 - 2 Consequences of transfer to another hospital	2 - 3 - 2 - 1 Switching hospitals has affected my family (changes in husband's place of work, registration of children in new
3 Diagnosis and treatment	3 - 1 Treatment	3 - 1 - 1 Choice of treatment method	3 - 1 - 1 - 1 Unable to decide what form of treatment to undergo
			3 - 1 - 1 - 2 Unable to make my own decisions regarding the form of treatment to undergo
			3 - 1 - 1 - 3 Worried whether my choice of treatment was correct
			3 - 1 - 1 - 4 Unable to easily choose the form of treatment to undergo because of a lack of sufficient knowledge
			3 - 1 - 1 - 5 Difficult to choose the form of treatment to undergo because of a lack of sufficient information
		3 - 1 - 2 Feelings regarding treatment	3 - 1 - 2 - 1 Lack of confidence in treatment
			3 - 1 - 2 - 2 Torn about what form of treatment to undergo
			3 - 1 - 2 - 3 Was told that my condition is untreatable
			3 - 1 - 2 - 4 Was told that there was no other form of treatment for my condition
			3 - 1 - 2 - 5 Treatment is painful
			3 - 1 - 2 - 6 Unable to decide whether or not to continue to undergo
			3 - 1 - 2 - 7 Can no longer continue to undergo the same form of treatment
			3 - 1 - 2 - 8 No schedule yet set for my treatment
			3 - 1 - 2 - 9 Unable to decide on my own when to undergo treatment
			3 - 1 - 2 - 10 Was unable to receive treatment until new medicine was
			3 - 1 - 2 - 11 Concerned that my condition might become worse while waiting for treatment
			3 - 1 - 2 - 12 Concerned whether a donor will ever be found (bone marrow transplant)
			3 - 1 - 2 - 13 Treatment cannot be performed as scheduled
			3 - 1 - 2 - 14 Concerned whether I will be able to deal with treatment
			3 - 1 - 2 - 15 Doctor has refused to treat me with new medicines I requested
			3 - 1 - 2 - 16 Fear and concern about side effects of cancer medicines
			3 - 1 - 2 - 17 Worried whether bone marrow transplant will work
			3 - 1 - 2 - 18 Worried about catching infectious diseases as a result of
			3 - 1 - 2 - 19 Concerned about the amount of time it takes until a program of treatment is decided upon
			3 - 1 - 2 - 20 Medicines used in treatment no longer work (i.e., have developed

		3 - 1 - 3 Feelings regarding treatment that stem from prior	3 - 1 - 3 - 1 Fear and concern about treatment from prior experience
			3 - 1 - 3 - 2 Resistance against treatment because of prior experience
		3 - 1 - 4 Feelings regarding surgery	3 - 1 - 4 - 1 Undergoing an operation (lack of trust, etc.)
			3 - 1 - 4 - 2 Fear and concern about operation
			3 - 1 - 4 - 3 Concerned about long wait to undergo operation
			3 - 1 - 4 - 4 Concerned that my condition might become worse while waiting for operation
			3 - 1 - 4 - 5 Have been told that an operation is difficult or impossible
			3 - 1 - 4 - 6 Regret have undergone surgery
			3 - 1 - 4 - 7 Worried whether I will be able to undergo an operation
		3 - 1 - 5 Other treatment methods	3 - 1 - 5 - 1 Other forms of treatment and information about same
			3 - 1 - 5 - 2 Use of alternative treatments, health foods, or other things
			3 - 1 - 5 - 3 Pain from side effects and other causes and treatment to improve condition
		3 - 1 - 6 Treatment policy	3 - 1 - 6 - 1 Treatment policies differ from one hospital to the next
			3 - 1 - 6 - 2 Treatment policies differ from one doctor to the next (within same hospital)
			3 - 1 - 6 - 3 Unable to agree with doctors' treatment policies
	3 - 2 Tests	3 - 2 - 1 Undergoing tests	3 - 2 - 1 - 1 Undergoing tests (e.g., lack of trust)
			3 - 2 - 1 - 2 Worried about undergoing tests
			3 - 2 - 1 - 3 Symptoms after testing (e.g., pain)
			3 - 2 - 1 - 4 Would like to have someone by my side when undergoing tests
			3 - 2 - 1 - 5 Tests are painful
		3 - 2 - 2 Test results	3 - 2 - 2 - 1 Afraid to ask about test results
4 Palliative care	4 - 1 Mental state at time of remission	4 - 1 - 1 Feelings regarding the period of palliative care	4 - 1 - 1 - 1 Would like to go peacefully
			4 - 1 - 1 - 2 Would like to see primary stress placed on quality of life
			4 - 1 - 1 - 3 Would like to be allowed to die peacefully and without pain
			4 - 1 - 1 - 4 Would like to be given palliative treatment which would make it possible to die without losing my senses
			4 - 1 - 1 - 5 Worried about physical pain during palliative treatment
			4 - 1 - 1 - 6 Do not want treatment to extend my life
		4 - 1 - 2 Constructive preparation for	4 - 1 - 2 - 1 Will take care of my financial affairs
			4 - 1 - 2 - 2 Management of estate
			4 - 1 - 2 - 3 Worried about taking care of my personal affairs and funeral
	4 - 2 Palliative care treatment and facilities	4 - 2 - 1 Palliative care treatment	4 - 2 - 1 - 1 (Palliative care) Would like to undergo treatment to relieve my pain
			4 - 2 - 1 - 2 (Palliative care) Want to know what kind of treatment I will be given
		4 - 2 - 2 Palliative care facilities	4 - 2 - 2 - 1 Have thought about or wish to undergo home care treatment
			4 - 2 - 2 - 2 Would like information about palliative care (e.g., places, costs, etc.)
5 Notification, informed consent, and second opinions	5 - 1 Notification	5 - 1 - 1 Notification method	5 - 1 - 1 - 1 Notice of my condition was delivered inappropriately
			5 - 1 - 1 - 2 Hospital insufficiently considerate of patients' feelings when giving notice of condition
			5 - 1 - 1 - 3 Lack of trust because of clear notification of my condition
	5 - 2 Informed consent	5 - 2 - 1 Informed consent at the hospital providing treatment	5 - 2 - 1 - 1 (At hospital where undergoing treatment) Insufficient explanation given by doctors
			5 - 2 - 1 - 2 (At hospital where undergoing treatment) Unable to understand doctor's explanation
			5 - 2 - 1 - 3 (At hospital where undergoing treatment) Insufficient
			5 - 2 - 1 - 4 (At hospital where undergoing treatment) Unable to agree with doctor's explanation
			5 - 2 - 1 - 5 (At hospital where undergoing treatment) Insufficient information (e.g., few symptoms)
			5 - 2 - 1 - 6 (At hospital where undergoing treatment) Was bothered by not having family or relatives at my side
			5 - 2 - 1 - 7 (At hospital where undergoing treatment) Doctor's explanation only worsened my fears
		5 - 2 - 2 Informed consent at other hospitals	5 - 2 - 2 - 1 (At other hospital) Insufficient explanation given by doctors
			5 - 2 - 2 - 2 (At other hospital) Unable to understand doctor's explanation
			5 - 2 - 2 - 3 (At other hospital) Insufficient information provided (e.g., about side effects)
			5 - 2 - 2 - 4 (At other hospital) Unable to agree with doctor's explanation
	5 - 3 Second opinions	5 - 3 - 1 Second opinions at the hospital providing treatment	5 - 3 - 1 - 1 Test results differ from one hospital to the next
			5 - 3 - 1 - 2 Obtaining information to get a second opinion
			5 - 3 - 1 - 3 Asking for a second opinion has made it more difficult to communicate with my first doctor
			5 - 3 - 1 - 4 Worried whether I ought to seek a second opinion
			5 - 3 - 1 - 5 The doctor I consulted for a second opinion gave a diagnosis which seems to be tailored to the concerns of my primary
			5 - 3 - 1 - 6 Would like to ask for a second opinion but my primary doctor does not think I should do so
6 Medical coordination	6 - 1 Coordination with local medical	6 - 1 - 1 Follow-up after completion of main treatment	6 - 1 - 1 - 1 Looks like I will be unable to visit a hospital further away because of shortness of breath or other symptoms

	6 - 2 Problems concerning coordination of mdical care	6 - 2 - 1 Lack of communication and information exchange in coordination of medical care	6 - 2 - 1 - 1 Burden placed on patient because of lack of communication and information exchange in coordination of medical care
7 Home care	7 - 1 Home care	7 - 1 - 1 Inability to visit a hospital	7 - 1 - 1 - 1 Visiting a hospital will become harder and harder because of
			7 - 1 - 1 - 2 Visiting a hospital will become harder and harder because of cancer or other sickness
		7 - 1 - 2 Desire for home care	7 - 1 - 2 - 1 Would like to undergo treatment at home because children are still young
8 Facility and equipment/access	8 - 1 Facilities and equipment	8 - 1 - 1 Facilities and equipment regarded as necessary	8 - 1 - 1 - 1 Would like to see hospital provide a place where patients can talk with each other
			8 - 1 - 1 - 2 Would like to see privacy protected in examination rooms
			8 - 1 - 1 - 3 Would like to see computers provided (in hospital) for finding information
			8 - 1 - 1 - 4 Would like to have privacy in multi-patient rooms
		8 - 1 - 2 Inappropriate facilities or equipment	8 - 1 - 2 - 1 There are postings in hospital which make patients nervous
			8 - 1 - 2 - 2 Dislike use of nameplates at entrances to patient rooms (shows insufficient concern for privacy)
			8 - 1 - 2 - 3 Atmosphere of hospital is depressing
	8 - 2 Visiting a hospital	8 - 2 - 1 Inconvenience of visiting the hospital	8 - 2 - 1 - 1 Difficult to go to hospital because of distance (patient/family)
			8 - 2 - 1 - 2 Difficult to go to hospital because of crowded public transportation
9 Relationships with medical staff (own hospital)	9 - 1 Relationships with medical staff (own hospital)	9 - 1 - 1 Feelings toward doctors and nurses (own hospital)	9 - 1 - 1 - 1 (Own hospital) Attitudes of doctors and nurses
			9 - 1 - 1 - 2 (Own hospital) Things doctors and nurses say
			9 - 1 - 1 - 3 (Own hospital) Words and behavior of medical personnel during examinations
			9 - 1 - 1 - 4 (Own hospital) Worry whether doctors really tell the truth
			9 - 1 - 1 - 5 (Own hospital) Doctors do not understand patients' feelings
			9 - 1 - 1 - 6 (Own hospital) Worry whether diagnoses are correct
			9 - 1 - 1 - 7 (Own hospital) Worry whether I have the right doctor
			9 - 1 - 1 - 8 (Own hospital) Lack of trust in diagnoses and treatment
			9 - 1 - 1 - 9 (Own hospital) Worry about whether I will be able to get along well with doctors and nurses
			9 - 1 - 1 - 10 (Own hospital) There is no one available to talk to for an informed opinion
			9 - 1 - 1 - 11 (Own hospital) Lack of trust in doctors because of their handling of persons close to self
		9 - 1 - 2 Difficulties in communicating with medical staff	9 - 1 - 2 - 1 Would like to be able to have sufficient time to talk with my doctors
			9 - 1 - 2 - 2 Difficult to ask questions of doctors (they seem too busy and I fail to ask)
			9 - 1 - 2 - 3 Time lags occur between regular visits and it is difficult to communicate properly with doctors
			9 - 1 - 2 - 4 I mistakenly entrusted everything to my doctor
			9 - 1 - 2 - 5 Difficult to communicate with doctors because of hearing
		9 - 1 - 3 Causes of difficulties in communication with medical staff	9 - 1 - 3 - 1 Medical staff do not share information sufficiently with each other
			9 - 1 - 3 - 2 Replacement of main treating physician
			9 - 1 - 3 - 3 Insufficient attention paid to mental needs (e.g., acting to provide advice)
			9 - 1 - 3 - 4 Unable to obtain advice from medical staff after discharge from hospital
		9 - 1 - 4 Medical malpractice	
	9 - 2 Relationships with medical institutions (own hospital)	9 - 2 - 1 Feelings toward the medical institution (own hospital)	9 - 2 - 1 - 1 (Own hospital) Lack of trust in treatment and care
			9 - 2 - 1 - 2 (Own hospital) Worried whether I have chosen the right
			9 - 2 - 1 - 3 Cooperation between different departments
			9 - 2 - 1 - 4 Provision of information on life after undergoing treatment
10 Relationships with medical staff (other hospital)	10 - 1 Relationships with medical staff (other hospitals)	10 - 1 - 1 Feelings toward doctors and nurses (other hospitals)	10 - 1 - 1 - 1 (Other hospitals) Attitudes of doctors and nurses
			10 - 1 - 1 - 2 (Other hospitals) Things doctors and nurses say
		10 - 1 - 2 Feelings toward medical staff other than doctors and nurses (other hospitals)	10 - 1 - 2 - 1 Was embarrassed when the words "anticancer drug" were said in a loud voice at a pharmacy outside the hospital
	10 - 2 Relationships with medical institutions (other hospitals)	10 - 2 - 1 Tests, diagnosis, and treatment at other hospitals	10 - 2 - 1 - 1 Lack of confidence in the tests, diagnoses, and treatment I have undergone
		10 - 2 - 2 Examination for treatment of conditions other than cancer	10 - 2 - 2 - 1 Has been stressful to talk about my medical history when being examined for things other than cancer

- 10 - 2 - 2 - 2 Do not want to have scars from operations seen when being examined for things other than cancer

- **11 Symptoms, side effects and after effects**
  - 11 - 1 Side effects and after effects of treatment
    - 11 - 1 - 1 Symptoms of side effects of anticancer drugs
      - 11 - 1 - 1 - 1 Loss of hair due to anticancer drugs
      - 11 - 1 - 1 - 2 Tingling of limbs due to anticancer drugs
      - 11 - 1 - 1 - 3 Nausea due to anticancer drugs
      - 11 - 1 - 1 - 4 Changes in appearance (blackening of fingernails and toenails, appearance of skin due to anticancer drugs）
      - 11 - 1 - 1 - 5 Other symptoms due to anticancer drugs (e.g., anemia)
      - 11 - 1 - 1 - 6 Precancerous symptoms due to anticancer drugs
    - 11 - 1 - 2 Continuation of side effects of anticancer drugs
      - 11 - 1 - 2 - 1 Long-term side effects of anticancer drugs
      - 11 - 1 - 2 - 2 Continuation of side effects of anticancer drugs
      - 11 - 1 - 2 - 3 Effects of side effects of Continuation of side effects of anticancer drugs on daily life
    - 11 - 1 - 3 Symptoms of side effects of irradiation therapy
      - 11 - 1 - 3 - 1 Skin inflammation as a side effect of irradiation (rashes, discoloration, itching)
      - 11 - 1 - 3 - 2 Headaches and/or nausea caused by irradiation therapy
      - 11 - 1 - 3 - 3 Other symptoms caused by irradiation therapy
      - 11 - 1 - 3 - 4 Continued respiratory symptoms occurring because of pneumonia brought on by irradiation therapy
    - 11 - 1 - 4 After effects of irradiation therapy
      - 11 - 1 - 4 - 1 (After effects of irradiation therapy) Dry mouth and pain in throat caused by lack of salivation
      - 11 - 1 - 4 - 2 (After effects of irradiation therapy) Effects on daily life caused by lack of salivation
      - 11 - 1 - 4 - 3 (After effects of irradiation therapy) Difficult to eat because of lack of salivation
      - 11 - 1 - 4 - 4 Other symptoms resulting from irradiation therapy
      - 11 - 1 - 4 - 5 Effects on eyesight resulting from irradiation therapy
      - 11 - 1 - 4 - 6 Effects of irradiation therapy on sense of taste or smell
      - 11 - 1 - 4 - 7 Effects of irradiation therapy on other after effects of ongoing irradiation treatment
      - 11 - 1 - 4 - 8 Other effects of irradiation therapy on daily life
    - 11 - 1 - 5 After effects of surgery
      - 11 - 1 - 5 - 1 Difficulty in walking due to after effects of operation
      - 11 - 1 - 5 - 2 Heavy sweating due to after effects of operation
      - 11 - 1 - 5 - 3 Excessive phlegm due to after effects of operation
      - 11 - 1 - 5 - 4 Unable to clear throat of phlegm due to after effects of
      - 11 - 1 - 5 - 5 Swelling due to after effects of operation
      - 11 - 1 - 5 - 6 Ongoing after effects of operation (pain, muscle stiffness)
      - 11 - 1 - 5 - 7 Other ongoing after effects of operation
      - 11 - 1 - 5 - 8 General listlessness due to after effects of operation
    - 11 - 1 - 6 Symptoms arising from urination problems
      - 11 - 1 - 6 - 1 Frequent urination
      - 11 - 1 - 6 - 2 Loss of bladder control
      - 11 - 1 - 6 - 3 Difficulty in urinating (i.e., takes time)
      - 11 - 1 - 6 - 4 Lack of urge to urinate
    - 11 - 1 - 7 Impact of urination problems on daily life
      - 11 - 1 - 7 - 1 Loss of sleep due to frequent urination caused by loss of bladder control
      - 11 - 1 - 7 - 2 Pain during urination
      - 11 - 1 - 7 - 3 Unable to spend long time outside due to loss of bladder
    - 11 - 1 - 8 Symptoms arising from dyschezia
      - 11 - 1 - 8 - 1 Constipation
      - 11 - 1 - 8 - 2 Diarrhea, frequent bowel movements, loss of bowel control
      - 11 - 1 - 8 - 3 Loss of urge for bowel movements
    - 11 - 1 - 9 Impact of dyschezia on daily life
      - 11 - 1 - 9 - 1 Irritation of frequent visits to the toilet when outside or at work due to dyschezia
      - 11 - 1 - 9 - 2 Soiling of undergarments due to dyschezia
      - 11 - 1 - 9 - 3 Need to be careful in front of other people due to dyschezia
      - 11 - 1 - 9 - 4 Insufficient sleep due to need to go to the toilet frequently due to dyschezia
      - 11 - 1 - 9 - 5 Inability to go outdoors due to excessive defecation
    - 11 - 1 - 10 Coping with a colostomy
      - 11 - 1 - 10 - 1 Coping with a colostomy
      - 11 - 1 - 10 - 2 Difficulty of daily handling of colostomy due to other problem
      - 11 - 1 - 10 - 3 Difficulty in attaching colostomy bag
      - 11 - 1 - 10 - 4 Difficult or impossible to attach colostomy bag by oneself because of other disability
      - 11 - 1 - 10 - 5 Worried whether I will be able to find a colostomy bag suited to my own body
      - 11 - 1 - 10 - 6 (Colostomy) Trapping of air filter due to difficulty in bowel
    - 11 - 1 - 11 Symptoms arising from a
      - 11 - 1 - 11 - 1 Pain in areas around colostomy
      - 11 - 1 - 11 - 2 Rashes and itching in areas around colostomy
    - 11 - 1 - 12 Stress arising from a colostomy
      - 11 - 1 - 12 - 1 Attaching colostomy bag causes stress
      - 11 - 1 - 12 - 2 (Colostomy) Unable to control bowel movements
      - 11 - 1 - 12 - 3 Must live with colostomy for the rest of my life
      - 11 - 1 - 12 - 4 Concern whether colostomy which should have been temporary may be permanent
    - 11 - 1 - 13 Impact of a colostomy on daily life
      - 11 - 1 - 13 - 1 Difficulty of dealing with daily life as a result of the need to attach colostomy bag
      - 11 - 1 - 13 - 2 Colostomy has restricted my daily life

	11 - 1 - 13 - 3 Colostomy has resulted in uncontrolled farting and bowel movements (worried about smell) 11 - 1 - 13 - 4 Unable to work because of colostomy (unable to concentrate) 11 - 1 - 13 - 5 Unable to travel because of colostomy 11 - 1 - 13 - 6 Difficult to leave home for long periods of time because of colostomy 11 - 1 - 13 - 7 Concerned about dealing with daily life in the future because of colostomy 11 - 1 - 13 - 8 Worried about the kinds of foods I eat to prevent diarrhea because of colostomy
11 - 1 - 14 Future colostomy management	11 - 1 - 14 - 1 Future colostomy management (i.e., when it becomes necessary to have someone care for me)
11 - 1 - 15 Symptoms arising from lymphedema	11 - 1 - 15 - 1 Lymphedema makes it difficult to raise my arms 11 - 1 - 15 - 2 Lymphedema causes muscle stiffness 11 - 1 - 15 - 3 Lymphedema causes tension 11 - 1 - 15 - 4 Lymphedema causes drowsiness 11 - 1 - 15 - 5 Lymphedema causes swelling
11 - 1 - 16 Impact of lymphedema on daily life	11 - 1 - 16 - 1 (Lymphedema) Physical and mental instability in daily life 11 - 1 - 16 - 2 Lymphedema restricts the clothes I can wear 11 - 1 - 16 - 3 Lymphedema makes it difficult to go out, do work, or do 11 - 1 - 16 - 4 (Lymphedema) Elastic stockings feel uncomfortable or difficult to wear 11 - 1 - 16 - 5 Forced to quit work because of lymphedema 11 - 1 - 16 - 6 (Lymphedema) Lack of energy due to inflammation
11 - 1 - 17 Impact of losing one’s voice on daily life	11 - 1 - 17 - 1 Unable to bathe naturally because of tracheostomy 11 - 1 - 17 - 2 Unable to talk on the telephone because of loss of voice 11 - 1 - 17 - 3 Concern about daily life in the future because of loss of voice
11 - 1 - 18 Impact of losing one’s voice on social activity	11 - 1 - 18 - 1 Unable to return to normal life because of loss of voice 11 - 1 - 18 - 2 Am stared at when I speak or use my voice machine 11 - 1 - 18 - 3 Have lost contact with other people because of loss of voice
11 - 1 -19 Communication difficulties resulting from the loss of one’s voice	11 - 1 - 19 - 1 (Loss of voice) Unable to have a conversation 11 - 1 - 19 - 2 (Loss of voice) Find it difficult to speak 11 - 1 - 19 - 3 (Loss of voice) Find it difficult to speak with family or other 11 - 1 - 19 - 4 (Loss of voice) Unable to express my feelings
11 - 1 - 20 Concerns in daily life arising from a gastrotomy	11 - 1 - 20 - 1 Concerns about daily life due to a gastrotomy 11 - 1 - 20 - 2 Mental pain of having to cook even when I can’t enjoy meals because of a gastrotomy 11 - 1 - 20 - 3 Don’t know what kind of foods I should eat because of a gastrotomy
11 - 1 - 21 Impact of a gastrotomy	11 - 1 - 21 - 1 Recovery from a gastrotomy 11 - 1 - 21 - 2 Unable to gain weight or have lost weight since a gastrotomy 11 - 1 - 21 - 3 Effects on other organs from a gastrotomy 11 - 1 - 21 - 4 Pain or sharp pangs from a gastrotomy 11 - 1 - 21 - 5 Bile rising in throat due to a gastrotomy 11 - 1 - 21 - 6 A gastrotomy has resulted in distending of stomach or farting
11 - 1 - 22 Impact of a gastrotomy on eating	11 - 1 - 22 - 1 Concerned about whether or not I will be able to obtain sufficient nutrition after operation 11 - 1 - 22 - 2 Concerned about whether or not I will be able to eat properly 11 - 1 - 22 - 3 Concerned about whether or not I will be able to eat enough after a gastrotomy 11 - 1 - 22 - 4 Find it difficult to eat aftera gastrotomy 11 - 1 - 22 - 5 Find my urge to eat lessened aftera gastrotomy 11 - 1 - 22 - 6 A gastrotomy has resulted in dampened feeling after meals 11 - 1 - 22 - 7 A gastrotomy has resulted in stomach pain after meals 11 - 1 - 22 - 8 No longer enjoy meals after a gastrotomy 11 - 1 - 22 - 9 Other effects on eating as a result of a gastrotomy
11 - 1 - 23 Symptoms arising from ileus (intestinal obstruction)	11 - 1 - 23 - 1 Bowel pain caused by ileus (intestinal obstruction) 11 - 1 - 23 - 2 Vomiting caused by ileus (intestinal obstruction) 11 - 1 - 23 - 3 Constipation or loss of ability to release gas caused by ileus (intestinal obstruction)
11 - 1 - 24 Impact of ileus (intestinal obstruction) on daily life	11 - 1 - 24 - 1 Repeated pain or stress caused by ileus (intestinal obstruction)
11 - 1 - 25 Symptoms arising from changes in hormone balance	11 - 1 - 25 - 1 Gain of weight caused by hormone treatment or other treatment 11 - 1 - 25 - 2 Hormone treatment or other treatment has resulted in chest 11 - 1 - 25 - 3 (Changes in hormone balance) Menopausal symptoms caused by organ removal 11 - 1 - 25 - 4 Hormone treatment or other treatment has resulted in irregularity in timing of periods 11 - 1 - 25 - 5 Hormone treatment or other treatment has resulted in excessive sweating or lengthening of time between periods 11 - 1 - 25 - 6 Hormone treatment or other treatment has resulted in eyesight problems

	11 - 1 - 26 Impact of changes in hormone balance on daily	11 - 1 - 26 - 1 (Changes in hormone balance) Unable to concentrate on work due to menopausal symptoms
		11 - 1 - 26 - 2 (Changes in hormone balance) Unable to sleep because of menopausal symptoms
	11 - 1 - 27 Symptoms arising from sexual dysfunction	11 - 1 - 27 - 1 Unable to engage in sex or lack of sexual desire due to sexual dysfunction
		11 - 1 - 27 - 2 Difficulty or inability to ejaculate
		11 - 1 - 27 - 3 Experience pain during sex due to sexual dysfunction
	11 - 1 - 28 Effects of sexual dysfunction on daily life	
	11 - 1 - 30 Symptoms arising from use of an artificial urinary	11 - 1 - 30 - 1 Future artificial bladder management
		11 - 1 - 30 - 2 Coping wiht artificial bladder
	11 - 1 - 31 Symptoms arising from use of an artificial urinary	11 - 1 - 31 - 1 Pain in areas around artificial bladder
		11 - 1 - 31 - 2 Rashes or itching in areas around artificial bladder
		11 - 1 - 31 - 3 Must live with artificial bladder for the rest of my life
	11 - 1 - 32 Stress arising from use of an artificial urinary bladder	
	11 - 1 - 33 Impact of use of an artificial urinary bladder on daily life	11 - 1 - 33 - 1 Smell of urine persistent because of artificial urinary bladder
		11 - 1 - 33 - 2 Unable to travel far from home because of artificial urinary
		11 - 1 - 33 - 3 Care of self difficult outside of home because of artificial
		11 - 1 - 33 - 4 Find it difficult to stay in hotels or go to public baths when traveling because of artificial urinary bladder
		11 - 1 - 33 - 5 Difficulty of dealing with daily life because of artificial urinary
	11 - 1 - 34 Effects of surgery on	11 - 1 - 34 - 1 Difficulty in talking because of operation (e.g., tongue cancer)
		11 - 1 - 34 - 2 Difficulty in swallowing because of operation
		11 - 1 - 34 - 3 Loss of sense of taste or smell because of operation
		11 - 1 - 34 - 4 Scar from operation hurts when bathing
		11 - 1 - 34 - 5 Difficult to sterilize scar from operation at home
		11 - 1 - 34 - 6 Unable to wear a seatbelt because of pain from scar from
	11 - 1 - 35 Effects on sexual acts	11 - 1 - 35 - 1 Worried about effects of having sex on my condition
11 - 2 Other continued symptoms or dysfunctions	11 - 2 - 1 Continued symptoms	11 - 2 - 1 - 1 Dizziness or shortness of breath when walking
		11 - 2 - 1 - 2 Shortness of breath whenever I move
		11 - 2 - 1 - 3 Physical problems (keloids, pain, itching)
		11 - 2 - 1 - 4 Languidity
		11 - 2 - 1 - 5 Pain
		11 - 2 - 1 - 6 Difficulty in speaking due to sickness
		11 - 2 - 1 - 7 Fever
		11 - 2 - 1 - 8 Pain in daily life due to hydronephrosis
		11 - 2 - 1 - 9 Other continuing symptoms
		11 - 2 - 1 - 10 Other GVHD (graft-versus-host disease) symptoms from transplant operation
		11 - 2 - 1 - 11 Long amount of time required for cut to heal because of
	11 - 2 - 2 Other dysfunctions	11 - 2 - 2 - 1 Liver dysfunction
		11 - 2 - 2 - 2 Kidney dysfunction
	11 - 2 - 3 Impact on everyday life of other side effects	11 - 2 - 3 - 1 (Other symptoms) Unable to eat favorite foods
		11 - 2 - 3 - 2 (Other symptoms) Suffer from stress from continued liquid diet
		11 - 2 - 3 - 3 (Other symptoms) Unable to taste food
		11 - 2 - 3 - 4 (Other symptoms) Suffer from coughing
		11 - 2 - 3 - 5 (Other symptoms) Suffer from insomnia or inability to fall into
		11 - 2 - 3 - 6 (Other symptoms) Easily tired
		11 - 2 - 3 - 7 (Other symptoms) Other effects on daily life
	11 - 2 - 4 Physical symptoms accompanying cancer	11 - 2 - 4 - 1 Coughing due to pleural fluid
		11 - 2 - 4 - 2 Putrefaction or necrosis of affected area
		11 - 2 - 4 - 3 Accumulation of peritoneal fluid (cancerous peritonitis)
		11 - 2 - 4 - 4 Pain in affected area
		11 - 2 - 4 - 5 Accumulation of pleural fluid (cancerous pleuritis)
		11 - 2 - 4 - 6 Anemic as a result of bone marrow seepage (spreading)
	11 - 2 - 5 Symptoms caused by diseases other than cancer	11 - 2 - 5 - 1 Symptoms from other disease
11 - 3 Life after treatment	11 - 3 - 1 Life and health management after treatment	11 - 3 - 1 - 1 Current health
		11 - 3 - 1 - 2 Future health management
		11 - 3 - 1 - 3 Future lifestyle management
		11 - 3 - 1 - 4 Effects of ongoing sickness or disability on daily life
		11 - 3 - 1 - 5 Unable to gain weight or have lost weight after treatment
		11 - 3 - 1 - 6 Loss of bodily strength or recovery of same after treatment
		11 - 3 - 1 - 7 Maintaining spirits after treatment
		11 - 3 - 1 - 8 Rehabilitation following treatment has been rough

- 11 - 3 - 2 The difference between life before the illness and now
  - 11 - 3 - 2 - 1 Unable to go on with life as planned
  - 11 - 3 - 2 - 2 Difficult to continue with ordinary life as I did before becoming
  - 11 - 3 - 2 - 3 Worry about whether I will be able to return to my ordinary
  - 11 - 3 - 2 - 4 Maintaining the quality of life I enjoyed before becoming sick

12 Anxiety and other mental problems

- 12 - 1 Anxiety
  - 12 - 1 - 1 Anxiety over spreading or recurrence
    - 12 - 1 - 1 - 1 Worry that the cancer might recur or spread
    - 12 - 1 - 1 - 2 Worry and fears about the recurrence of spreading of cancer
  - 12 - 1 - 2 Vague feeling of anxiety about
    - 12 - 1 - 2 - 1 Fear that I may become physically disabled
    - 12 - 1 - 2 - 2 Fear that symptoms of pain might appear
    - 12 - 1 - 2 - 3 Worry about whether I will be able to maintain or recover my bodily strength
    - 12 - 1 - 2 - 4 Worries about the effects of treatment and the time of treatment
    - 12 - 1 - 2 - 5 whether the disease would be wholly or partly cured
    - 12 - 1 - 2 - 6 There may be side effects or after effects
    - 12 - 1 - 2 - 7 Vague worries about cost of treatment and economic effects
    - 12 - 1 - 2 - 8 Vague worries about future and inability to make decisions about same (unable to think)
    - 12 - 1 - 2 - 9 Worried about what sort of symptoms might appear
    - 12 - 1 - 2 - 10 Worried about how far the disease has progressed
    - 12 - 1 - 2 - 11 Worried that I might be susceptible to other diseases
    - 12 - 1 - 2 - 12 Worried that I may never be able to marry
    - 12 - 1 - 2 - 13 Vague worries about diet
    - 12 - 1 - 2 - 14 Vague worries about family and household
    - 12 - 1 - 2 - 15 Vague worries about whether I will be able to return to my original life
  - 12 - 1 - 3 Changes in relationships with close family after cancer
    - 12 - 1 - 3 - 1 Worried that my sickness might lead to divorce
    - 12 - 1 - 3 - 2 Worried about finding people to talk with
- 12 - 2 Perception of cancer and death
  - 12 - 2 - 1 Perception of death
    - 12 - 2 - 1 - 1 wondering how long I have left to live
    - 12 - 2 - 1 - 2 Equating cancer with death
    - 12 - 2 - 1 - 3 Worried about when, where, and how I will die
    - 12 - 2 - 1 - 4 Worried about what will happen after my death (e.g., worried about what will happen to business)
    - 12 - 2 - 1 - 5 Worried about others (close to me) with the same sickness as well as about my own death
    - 12 - 2 - 1 - 6 Fear of death
  - 12 - 2 - 2 Perception of cancer
    - 12 - 2 - 2 - 1 Think about cancer while I wait for test results
    - 12 - 2 - 2 - 2 Connecting my physical problems with cancer
    - 12 - 2 - 2 - 3 Strong mental pressure caused by hearing the word 'cancer'
    - 12 - 2 - 2 - 4 Anxiety of identifying oneself with sufferers of the same disease
- 12 - 3 Varied emotions
  - 12 - 3 - 1 Mental panic and a loss of hope
    - 12 - 3 - 1 - 1 shock (massive psychological impact, feeling as if one’s mind has gone completely blank
    - 12 - 3 - 1 - 2 Denial (feeling that it cannot be cancer or inability to believe that it is)
    - 12 - 3 - 1 - 3 Loss of hope/breakdown ("it’s the end", "the treatment won’t work", "the future is pitch black")
    - 12 - 3 - 1 - 4 Why me?
    - 12 - 3 - 1 - 5 Confusion (unable to collect one’s thoughts)
    - 12 - 3 - 1 - 6 Grief and/or distress
    - 12 - 3 - 1 - 7 Insomnia/Inability to eat properly
    - 12 - 3 - 1 - 8 Despair
    - 12 - 3 - 1 - 9 Loneliness
    - 12 - 3 - 1 - 10 Unable to come to terms with sickness
    - 12 - 3 - 1 - 11 Negative thoughts
    - 12 - 3 - 1 - 12 Grief and pain over continuing of negative events
    - 12 - 3 - 1 - 13 Fear
    - 12 - 3 - 1 - 14 Regret (i.e., if only I had had myself tested earlier, stopped smoking, or been more careful about my diet)
    - 12 - 3 - 1 - 15 Anger, disappointment
    - 12 - 3 - 1 - 16 Worried because I no longer run into people with the same sickness who I formerly met when going to the hospital
  - 12 - 3 - 2 Continuous psychological anxiety
    - 12 - 3 - 2 - 1 Depression
    - 12 - 3 - 2 - 2 Always feeling insecure
    - 12 - 3 - 2 - 3 Loss of will
    - 12 - 3 - 2 - 4 Unable to believe that treatment will work
    - 12 - 3 - 2 - 5 Inability to control emotions
    - 12 - 3 - 2 - 6 (Sometimes) feel that I want to die
    - 12 - 3 - 2 - 7 Worried because of lack of knowledge
    - 12 - 3 - 2 - 8 Have become cut off from other people
    - 12 - 3 - 2 - 9 Have become dependent on alcohol
- 12 - 4 Depression
  - 12 - 4 - 1 Depression caused by social reasons
    - 12 - 4 - 1 - 1 Depression caused by financial problems
    - 12 - 4 - 1 - 2 Depression caused by problems with children
    - 12 - 4 - 1 - 3 Depression caused by problems with work

- 12 - 4 - 2 Depression caused by feeling of hopelessness about the
  - 12 - 4 - 2 - 1 Have no hope for the future and have become depressed and wish to die
- 12 - 4 - 3 Depression caused by physical reasons
  - 12 - 4 - 3 - 1 Depression caused by repeated recurrences

13 Way of living, reasons for living, set of values

- 13 - 1 View of life
  - 13 - 1 - 1 Feelings of meaninglessness
  - 13 - 1 - 2 Life and death
    - 13 - 1 - 2 - 1 Taking care of personal affairs
    - 13 - 1 - 2 - 2 The meaning of living
    - 13 - 1 - 2 - 3 Re-questioning one's own life
    - 13 - 1 - 2 - 4 Looking for a way to die
    - 13 - 1 - 2 - 5 Feeling that you are living for treatment because of the progress of the disease
    - 13 - 1 - 2 - 6 Question as to whether you should place a higher priority on career advancement or on your life (i.e., treatment)
    - 13 - 1 - 2 - 7 Question as to whether you should place a higher priority on caring for your parents on your life (i.e., treatment)
- 13 - 2 Way of living
  - 13 - 2 - 1 Approach to life after having suffered from cancer
    - 13 - 2 - 1 - 1 How to deal with disease
    - 13 - 2 - 1 - 2 Living with disease
    - 13 - 2 - 1 - 3 How to live your life from here on
    - 13 - 2 - 1 - 4 Your future daily life
    - 13 - 2 - 1 - 5 Can you battle the disease?
    - 13 - 2 - 1 - 6 Can you change yourself?
    - 13 - 2 - 1 - 7 Loss of the will to live
- 13 - 3 Self-identity
  - 13 - 3 - 1 External physical changes
    - 13 - 3 - 1 - 1 Pain caused by changes in personal appearance
    - 13 - 3 - 1 - 2 Choice of underwear and clothing (changes in physique as a result of surgery)
    - 13 - 3 - 1 - 3 Worry about changes in personal appearance
    - 13 - 3 - 1 - 4 Do not want spouse to see changes in personal appearance
    - 13 - 3 - 1 - 5 Stressful to go out because of changes in personal appearance
    - 13 - 3 - 1 - 6 Changes in personal appearance make it impossible to put yourself forward (i.e., shy)
    - 13 - 3 - 1 - 7 Breast restoration
    - 13 - 3 - 1 - 8 Do not want others to see changes in personal appearance
  - 13 - 3 - 2 Awareness and changes in awareness of one's own femininity or masculinity
    - 13 - 3 - 2 - 1 Fear about losing one's femininity
    - 13 - 3 - 2 - 2 Loss of or changes in one's femininity
    - 13 - 3 - 2 - 3 Anxieties about self-identity and ability to maintain masculine
    - 13 - 3 - 2 - 4 Changes or loss of masculine sexuality
    - 13 - 3 - 2 - 5 Spouse no longer seeks physical contact
    - 13 - 3 - 2 - 6 Have become unable to bear children because of treatment or loss of organs
  - 13 - 3 - 3 Changes in one's own awareness of self
    - 13 - 3 - 3 - 1 Unable to accept myself
    - 13 - 3 - 3 - 2 Feeling of self-pity
    - 13 - 3 - 3 - 3 Feeling of self-blame
    - 13 - 3 - 3 - 4 Fear of becoming unable to take care ofmyself
    - 13 - 3 - 3 - 5 Feeling that my existence is meaningless
    - 13 - 3 - 3 - 6 Find myself withdrawing when coming into contact with others

14 Work and financial burdens

- 14 - 1 Financial problems
  - 14 - 1 - 1 Effects of financial burdens caused by cancer
    - 14 - 1 - 1 - 1 Payment of mortgage
    - 14 - 1 - 1 - 2 Children's tuition
    - 14 - 1 - 1 - 3 Repayment of loan (for business)
    - 14 - 1 - 1 - 4 No longer as easy as it was to obtain a mortgage
  - 14 - 1 - 2 Medical expenses
    - 14 - 1 - 2 - 1 Cost of medical treatment; excessive cost of same
    - 14 - 1 - 2 - 2 Have no idea what medical treatment will cost
    - 14 - 1 - 2 - 3 Do not know how long you will have to continue paying for medical treatment
    - 14 - 1 - 2 - 4 Increase in the amount you have to pay for medical treatment (from 20 to 30 percent)
    - 14 - 1 - 2 - 5 Worried about whether you will be able to continue to pay for medical treatment
    - 14 - 1 - 2 - 6 Feeling of dissatisfaction about high medical bills
    - 14 - 1 - 2 - 7 Have become ineligible for insurance
    - 14 - 1 - 2 - 8 Fearful or worried about medical expenses because you are not covered by insurance
    - 14 - 1 - 2 - 9 Worried about medical expenses because you will become ineligible for further disability benefits under health insurance
    - 14 - 1 - 2 - 10 Cost of bone marrow transplant is high and not covered by insurance
    - 14 - 1 - 2 - 11 Unable to (or have given up on) be examined or treated by a physician because you have too little income
    - 14 - 1 - 2 - 12 Unable to undergo interferon treatment because it is not covered by insurance

		14 - 1 - 2 - 13 Frequently need to pay for medical expenses because of repeated short hospitalizations
		14 - 1 - 2 - 14 Financial worries caused by expiration of eligibility for hospitalization insurance under your life insurance plan
		14 - 1 - 2 - 15 Financial worry or dissatisfaction because you cannot be certified as being disabled
		14 - 1 - 2 - 16 Unable to go to hospital until you receive welfare (i.e., you cannot pay for treatment)
	14 - 1 - 3 Financial anxieties about one's future livelihood	14 - 1 - 3 - 1 You must work even if you shouldn't because you need the income
		14 - 1 - 3 - 2 Worry about your financial security
		14 - 1 - 3 - 3 Worry about your financial security in old age
		14 - 1 - 3 - 4 Worry about the future because you are unable to purchase or renew insurance
	14 - 1 - 4 Reduced income as a result of cancer	14 - 1 - 4 - 1 Reduced income as a result of cancer
		14 - 1 - 4 - 2 Income has fallen because your spouse has quit work to take care of you
	14 - 1 - 5 Expenses towards treatments and other things not covered by insurance	14 - 1 - 5 - 1 Cost of purchasing colostomy bags and artificial bladder bags
		14 - 1 - 5 - 2 Cost of alternative treatments and/or health foods
		14 - 1 - 5 - 3 Cost of purchasing disposable goods (e.g., gauze) for treatment
		14 - 1 - 5 - 4 Cost of treatment for lymphedema or related devices
		14 - 1 - 5 - 5 Cost of purchasing medicines not covered by insurance
		14 - 1 - 5 - 6 Cost of toupees or wigs
14 - 2 Problems concerning work	14 - 2 - 1 Impact of cancer on work	14 - 2 - 1 - 1 No longer able to continue at the same type of work as before
		14 - 2 - 1 - 2 Worried about being able to find work or find it difficult to find work
		14 - 2 - 1 - 3 Worried about what will happen if I take an extended leave from work
		14 - 2 - 1 - 4 Had to quit work
		14 - 2 - 1 - 5 Treated as a nonessential person at work
		14 - 2 - 1 - 6 Changes have occurred in compensation and work environment
		14 - 2 - 1 - 7 Have suffered as an employee (or may do so)
		14 - 2 - 1 - 8 Personally difficult to notify my workplace of the nature of my sickness or to write the name of the disease on forms (when applying for leave or when returning from leave)
		14 - 2 - 1 - 9 Unable to work properly because of the amount I eat or the times at which I eat
		14 - 2 - 1 - 10 Have failed to get a job I had already been accepted for
	14 - 2 - 2 Anxieties about going back to work or continuing work	14 - 2 - 2 - 1 (Employers) going back to work and physical strength
		14 - 2 - 2 - 2 (Employers) Worry about whether employee be able to continue work
		14 - 2 - 2 - 3 (Employers) Worry about whether employee will go back to
		14 - 2 - 2 - 4 (Employers) Worry about how long it will take before employee
		14 - 2 - 2 - 5 (Employers) Wonder whether employee should leave work
		14 - 2 - 2 - 6 (Employers) Concern that employee will need more vacation days for treatment, going to the hospital, and undergoing tests (concern that employee may quit)
		14 - 2 - 2 - 7 (Employers) Concern whether employee will be able to work as well as before
		14 - 2 - 2 - 8 (Employers) Concern that employee cannot concentrate properly on treatment because of continuing to work
		14 - 2 - 2 - 9 (Employers) Unable to rest after eating at workplace even when one wants to do so
		14 - 2 - 2 - 10 (Employers) Concern about combining work with treatment without problems
		14 - 2 - 2 - 11 (Employers) Concern about combining family duties with treatment without problems
	14 - 2 - 3 Anxieties about going back to work or continuing work (operators of businesses and self-employed persons)	14 - 2 - 3 - 1 (Owners and operators of businesses and self-employed persons) Difficult to continue working
		14 - 2 - 3 - 2 (Owners and operators of businesses and self-employed persons) Wonder whether I should continue with business
		14 - 2 - 3 - 3 Concern as to whether I can continue to work as a business
		14 - 2 - 3 - 4 (Owners and operators of businesses and self-employed persons) Organization and disposal of duties
		14 - 2 - 3 - 5 (Owners and operators of businesses and self-employed persons) Worries and concerns about finding a successor
		14 - 2 - 3 - 6 (Owners and operators of businesses and self-employed persons) Have hidden the fact that I have cancer from clients
		14 - 2 - 3 - 7 (Owners and operators of businesses and self-employed persons) Returning to work and physical strength
		14 - 2 - 3 - 8 Suspension of business
		14 - 2 - 3 - 9 (Owners and operators of businesses and self-employed persons) Would cause trouble amongst clients and best
		14 - 2 - 3 - 10 Combination of personal business with family duties
		14 - 2 - 3 - 11 (Owners and operators of businesses and self-employed persons) No longer treated seriously by my banker
	14 - 2 - 4 Personal relationship in the	14 - 2 - 4 - 1 Heavy feelings with respect to workplace

		workplace	14 - 2 - 4 - 2 Personal relationships at workplace (concern about others feelings about myself)
			14 - 2 - 4 - 3 Personal relationships at workplace (sympathy from other difficult and hard to bear)
			14 - 2 - 4 - 4 People at workplace don’t understand what it means to have cancer
			14 - 2 - 4 - 5 Have come to avoid people at my workplace
			14 - 2 - 4 - 6 Everyone at my workplace now knows I have cancer
			14 - 2 - 4 - 7 Do not want others at my workplace to know I have cancer
		14 - 2 - 5 Anxieties about being fired	14 - 2 - 5 - 1 Concerned that I may be fired
			14 - 2 - 5 - 2 Have been fired
15 Relationships with family and other people	15 - 1 Relationships with society	15 - 1 - 1 Reactions from surrounding people once disease	15 - 1 - 1 - 1 Am treated as a leper
			15 - 1 - 1 - 2 Advice from others (e.g., about religion or proper foods) is hard
			15 - 1 - 1 - 3 Reaction of others to cancer
			15 - 1 - 1 - 4 People don’t understand what it means to have cancer
			15 - 1 - 1 - 5 Have been told by others that I was destined to get cancer
			15 - 1 - 1 - 6 Have lost friends or find friends avoiding me
			15 - 1 - 1 - 7 Social bias against cancer
		15 - 1 - 2 Dealing with friends, acquaintances and neighbors	15 - 1 - 2 - 1 Worry about how to deal with friends and acquaintances (do not want them to know that I am sick)
			15 - 1 - 2 - 2 Worry about how to deal with friends and acquaintances (do not want their pity)
			15 - 1 - 2 - 3 Telling others (timing of notification)
			15 - 1 - 2 - 4 Dealing with neighbors and acquaintance at times of recurrence
			15 - 1 - 2 - 5 Unable to speak with people close to me about fear of death
			15 - 1 - 2 - 6 Do not want family or relatives to know about cancer
			15 - 1 - 2 - 7 Do not want neighbors to know about cancer
			15 - 1 - 2 - 8 Position towards society
			15 - 1 - 2 - 9 Behaving in such a manner as to prevent others from learning about cancer
		15 - 1 - 3 Isolation from society	15 - 1 - 3 - 1 Lack of a desire to go out
			15 - 1 - 3 - 2 No one to talk to or rely upon
			15 - 1 - 3 - 3 Feel distant from other people (or am growing more distant)
			15 - 1 - 3 - 4 Have no desire to meet with other people
			15 - 1 - 3 - 5 Unable to find personal guarantor (no family)
			15 - 1 - 3 - 6 No one to take care of me
		15 - 1 - 4 Impact on social life	15 - 1 - 4 - 1 Restrictions on social activities
			15 - 1 - 4 - 2 Effects on free time
		15 - 1 - 5 Anxieties regarding future social activities	15 - 1 - 5 - 1 Wonder whether I will be able to return to an ordinary social life or return to society
			15 - 1 - 5 - 2 Concerned about whether I will be able to adjust to social
			15 - 1 - 5 - 3 Live alone and am worried about my life from now
		15 - 1 - 6 Relationships with local people	15 - 1 - 6 - 1 Difficult to play a role in local society
			15 - 1 - 6 - 2 Burden on family has increased because of inability to play a role in local society
		15 - 1 - 7 Relationships with other patients	15 - 1 - 7 - 1 Wonder whether I will be able to meet people with the same sickness
			15 - 1 - 7 - 2 Nobody of my age with the same sickness
			15 - 1 - 7 - 3 Death of friends with same sickness have left me with no one to
			15 - 1 - 7 - 4 Don’t know how to deal with people with same sickness in worse condition than myself
		15 - 1 - 8 Increase in stress regarding society	15 - 1 - 8 - 1 Stress as a result of personal relationships
			15 - 1 - 8 - 2 Have been refused as a marriage partner because I am unable to have children
			15 - 1 - 8 - 3 Have been refused as a marriage partner because of cancer
			15 - 1 - 8 - 4 Reaction of others to my having become unable to have
		15 - 1 - 9 Information and the media	15 - 1 - 9 - 1 Unable to get the information I want
			15 - 1 - 9 - 2 Too much information
			15 - 1 - 9 - 3 Information from news makes me (even more) worried
			15 - 1 - 9 - 4 Concern about reliability of information in news
			15 - 1 - 9 - 5 Want to know how to get information on being a cancer
	15 - 2 Relationships with family	15 - 2 - 1 Relationship with spouse	15 - 2 - 1 - 1 Feeling sorry about my spouse
			15 - 2 - 1 - 2 Unable to live up to my promises to my spouse
			15 - 2 - 1 - 3 Mental burden on my spouse
			15 - 2 - 1 - 4 Extra burden placed on spouse because of housework
			15 - 2 - 1 - 5 Effect on spouse’s work
			15 - 2 - 1 - 6 Financial burden on spouse
			15 - 2 - 1 - 7 Feeling that a change has occurred in relationships with spouse (that spouse has become more distant)
			15 - 2 - 1 - 8 Leaving my spouse widowed
			15 - 2 - 1 - 9 Wonder whether spouse will take care of you
			15 - 2 - 1 - 10 Worrying about aged and sick spouse
			15 - 2 - 1 - 11 Worrying about spouse’s future

	15 - 2 - 1 - 12	Concern about burden placed on spouse
15 - 2 - 2 Problems pertaining to relationship with spouse	15 - 2 - 2 - 1	Divorce or separation
	15 - 2 - 2 - 2	Both partners contracting an illness at the same time
	15 - 2 - 2 - 3	Not gaining enough support from the key figure in my life
	15 - 2 - 2 - 4	Spouse knows nothing
	15 - 2 - 2 - 5	Spouse shows no interest
	15 - 2 - 2 - 6	Lack of understanding on the part of my spouse
	15 - 2 - 2 - 7	Sexual relationships
	15 - 2 - 2 - 8	Hit out for no reason at spouse
	15 - 2 - 2 - 9	Have been beaten or received cold treatment or words from spouse
	15 - 2 - 2 - 10	Unable to concentrate on treatment because of need to care for spouse
	15 - 2 - 2 - 11	Have been forced to live apart to undergo treatment
15 - 2 - 3 Relationship with family	15 - 2 - 3 - 1	Unable to take care of parents (or grandparents)
	15 - 2 - 3 - 2	Family forced to perform household chores
	15 - 2 - 3 - 3	Have caused worry for my family
	15 - 2 - 3 - 4	Separation from family
	15 - 2 - 3 - 5	Have placed a financial burden on my family
	15 - 2 - 3 - 6	Have placed burden on my family
	15 - 2 - 3 - 7	Concern about placing elderly parents in nursing home or where to do so
	15 - 2 - 3 - 8	Feel apologetic towards family and do not want to cause them trouble
	15 - 2 - 3 - 9	Cannot die before one’s own parents (including in-laws)
	15 - 2 - 3 - 10	Family does not understand sickness or the feelings of one who is sick
	15 - 2 - 3 - 11	Hit out at family for no reason
	15 - 2 - 3 - 12	Worry of family is a burden
15 - 2 - 4 Increase in stress in relationship with the family	15 - 2 - 4 - 1	Living with parents of spouse
	15 - 2 - 4 - 2	Words and behavior of spouse’s parents
	15 - 2 - 4 - 3	Diet and number of meals of family members differ
	15 - 2 - 4 - 4	No longer treated with consideration by family once time has passed since the beginning of the disease
	15 - 2 - 4 - 5	Financial burden caused by lack of understanding by spouse
	15 - 2 - 4 - 6	Increase in stress because of spouse’s sickness
	15 - 2 - 4 - 7	Increase in stress because of need to take care of family members living together by oneself
	15 - 2 - 4 - 8	Unable to concentrate on treatment because of family duties
	15 - 2 - 4 - 9	Doing housework is a burden
	15 - 2 - 4 - 10	Was refused by family member to act as a donor
	15 - 2 - 4 - 11	Family is cold or shows no interest
	15 - 2 - 4 - 12	Unable to concentrate on treatment because of family problems
15 - 2 - 5 Informing the family, etc.	15 - 2 - 5 - 1	Notifying family (parents)
	15 - 2 - 5 - 2	Notifying family (children)
	15 - 2 - 5 - 3	Notifying family (spouse)
	15 - 2 - 5 - 4	How to tell family, friends, and other people
	15 - 2 - 5 - 5	Do now want family, friends, and other people to know about
15 - 2 - 6 Familial concerns	15 - 2 - 6 - 1	Concern about how family is going to live
	15 - 2 - 6 - 2	Concern about parent’s lives and taking care of parents
	15 - 2 - 6 - 3	Concern about aged, sick, disabled family
	15 - 2 - 6 - 4	Concerned about what will happen to family when you are
	15 - 2 - 6 - 5	Concerned about cancer in family members with the same lifestyle as yourself
15 - 2 - 7 Relationship with children	15 - 2 - 7 - 1	Unable to take care of children properly
	15 - 2 - 7 - 2	Unable to participate in children’s school or events (feel as if there will be less and less that you will be able to do for your
	15 - 2 - 7 - 3	Effect on physical or mental health of children
	15 - 2 - 7 - 4	Worrying that the disease will be passed on to my children
	15 - 2 - 7 - 5	Putting children in someone else’s care and finding someplace to do so
	15 - 2 - 7 - 6	Fear that you might transmit sickness to children (e.g., in cases of type C hepatitis)
	15 - 2 - 7 - 7	Do not want to trouble children
	15 - 2 - 7 - 8	Children show resistance to personal contact because of changes in physical appearance
	15 - 2 - 7 - 9	Unwilling to participate in children’s school events because of changes in physical appearance
	15 - 2 - 7 - 10	Placing a financial burden on children
	15 - 2 - 7 - 11	Unable to concentrate on treatment because of need to care for children
15 - 2 - 8 Concern about children	15 - 2 - 8 - 1	Worry and concern about leaving children behind
	15 - 2 - 8 - 2	Concern about children who have not yet reached 18
	15 - 2 - 8 - 3	Concern about being unable to raise children to succeed you
	15 - 2 - 8 - 4	Concern about how long you have left to spend with your
	15 - 2 - 8 - 5	Concern about children growing up in a one-parent household
	15 - 2 - 8 - 6	Concern about children with disabilities
	15 - 2 - 8 - 7	Concern about sick children
15 - 2 - 9 Anxieties about pregnancy, giving birth, and raising	15 - 2 - 9 - 1	Pregnancy (giving birth)
	15 - 2 - 9 - 2	Would like to have another child

	15 - 2 - 9 - 3 Concern about (safely) giving birth
	15 - 2 - 9 - 4 Pain from not being able to breast-feed child
	15 - 2 - 9 - 5 Concern about raising children in future
	15 - 2 - 9 - 6 Concern about cancer treatment while pregnant
	15 - 2 - 9 - 7 Concern about what effects treatment during pregnancy might have on child
	15 - 2 - 9 - 8 Abortion of child to receive treatment
15 - 2 - 11 Disagreements with family	15 - 2 - 11 - 1 Disagreement with spouse about how to approach treatment
	15 - 2 - 11 - 2 Disagreement with family about how to approach treatment
	15 - 2 - 11 - 3 Family members or others have taken it upon themselves to decide how you should be treated

Appendix 2 Top 20 anxieties and burdens by category

Rank	Around the time of diagnosis		From diagnosis until the present time		Currently		Three stages total	
	Tertiary category	Number of cases	Tertiary category	Number of cases	Tertiary category	Number of cases	Tertiary category	Number of cases
1	Vague feeling of anxiety about the future	1,915	Anxiety over spreading or recurrence	1,304	Anxiety over spreading or recurrence	2,066	Anxiety over spreading or recurrence	4,033
2	Mental panic and a loss of hope	1,736	Vague feeling of anxiety about the future	603	Vague feeling of anxiety about the future	569	Vague feeling of anxiety about the future	3,087
3	Perception of death	1,674	Symptoms side effects of anticancer drugs	495	Medical expenses	333	Perception of death	2,177
4	Anxiety over spreading or recurrence	663	Mental panic and a loss of hope	300	Life and health management after treatment	258	Mental panic and a loss of hope	2,116
5	Concern about children	360	Perception of death	287	Perception of death	216	Symptoms side effects of anticancer drugs	673
6	Feelings regarding surgery	344	Perception of cancer	235	Perception of cancer	207	Perception of cancer	606
7	Family concerns	293	Feelings regarding treatment	219	Continued symptoms	194	Continuous psychological anxiety	561
8	Continuous psychological anxiety	249	Continuous psychological anxiety	196	Financial anxieties about one’s future livelihood	177	Medical expenses	506
9	Relationship with family	242	After effects of surgery	170	Symptoms side effects of anticancer drugs	157	Feelings regarding surgery	501
10	Impact of cancer on work	196	Life and health management after treatment	164	Impact on everyday life of other side effects	140	Feelings regarding treatment	493
11	Anxieties about going back to work or continuing work (Employers)	191	Continued symptoms	156	Feelings regarding treatment	139	Concern about children	470
12	Relationship with spouse	179	Feelings toward doctors and nurses (own hospital)	154	External physical changes	133	Anxieties about going back to work or continuing work (Employers)	431
13	Approach to life after having suffered from cancer	172	Medical expenses	152	After effects of surgery	124	Life and health management after treatment	429
14	Perception of cancer	164	Anxieties about going back to work or continuing work (Employers)	137	Continuous psychological anxiety	116	Family concerns	423
15	Choice of treatment method	139	Feelings regarding surgery	132	Symptoms arising from dyschezia	111	Relationship with family	412
16	Feelings regarding treatment	135	External physical changes	132	Approach to life after having suffered from cancer	108	External physical changes	380
17	Relationship with children	133	Impact of a gastrotomy on eating	126	Anxieties about going back to work or continuing work (Employers)	103	Approach to life after having suffered from cancer	360
18	External physical changes	115	Symptoms arising from dyschezia	112	Impact of a gastrotomy on eating	96	Continued symptoms	357
19	Informing the family, etc.	111	Choice of treatment method	103	Symptoms arising from lymphedema	93	Impact of cancer on work	336
20	Anxieties about going back to work or continuing work (operators of business and self-employers)	93	Informed consent	99	Mental panic and a loss of hope	80	Relationship with spouse	323

Appendix 3 Common responses in each category of the free answer section

1 Outpatient

1-1-2	**Outpatient treatment**	• Waiting 3 hours to be examined is both physically and mentally exhausting. • Anticancer drugs are administered weekly in outpatient treatment, even though this is physically burdensome.
1-2-1	**Choice of hospital**	• When it comes to having a cancer operation, which is the best hospital? (Confusion caused by differences among hospitals in treatment methods and attitudes towards patients.) • Since my children are young, treatment at which hospital would be best for my family and me?
1-2-2	**Choice of doctor**	• As my children were young, I was anxious about whether or not I would be able to find a doctor to whom I could confidently entrust my life.

2 Hospitalization/discharge/hospital change

2-1-2	**Prior to hospitalization**	• Waiting to be admitted to hospital after learning my diagnosis was a living hell as my anxiety grew daily. I will never forget this period in my life when I had no one with whom I could talk about my wide-ranging fears. • Although I was diagnosed with cancer, I had to wait about 2 weeks to be admitted to hospital as there were no beds immediately available. During that time I was consumed by fear that the cancer would progress or spread.
2-1-3	**Feelings regarding hospitalization**	• In hospital, the other patients would speak so graphically I frequently wanted to cover my ears. How much more reassured at those times I would have felt had things been explained properly to me by medical staff. • As I have been in and out of hospital with Hepatitis C-induced liver cancer, I am so worried about whether I will continue to be in and out of hospital that I feel depressed everyday.
2-2-2	**Discharge from hospital**	• Because I had changed wards during my hospital stay, I didn’t know anyone with the same condition as myself, and I spent every day worrying about when I could be discharged. • I had misgivings about returning home as I had been told I was to be discharged at a time when I was still unconfident about my physical and spiritual strength. I consulted my doctor, who recommended another hospital. I was transferred there and discharged after 4 weeks.
2-3-1	**Feelings regarding transfer to another hospital**	• With this hospital, I am full of doubts that I will receive proper treatment and pain control if I suffer a relapse. I am even thinking of changing hospitals. • I want to transfer to another hospital but feel I can’t say anything for fear of offending my doctor. • I will be retiring in a year and plan to return to my hometown. I want to continue receiving treatment in Tokyo, but am concerned about whether or not I can continue to receive the same high standard of treatment as I have had up until now.
2-3-2	**Consequences of transfer to another hospital**	• I had to transfer to another hospital in order to continue treatment; consequently, I had many worries, including concerns over such major lifestyle changes necessitated by my hospital transfer as my husband having to change jobs and my children change schools.

3 Treatment

3-1-1	**Choice of treatment method**	• Simply being told I had cancer was a shock; on top of that was the cruelty of having to overcome that shock and make many decisions in a very short time. There was the difficulty of having to make the decisions for myself in the end, even though I was given some advice. • Several anticancer drugs were explained to me and I was told to choose one of them, but I wasn't able to. In such a situation, to whom should I go for advice? • With the date of my operation set for 10 days after I learned my diagnosis, I had no time to acquire basic knowledge about my condition and so it was very difficult for me to go so far as to decide for myself the extent of the excision.
3-1-2	**Feelings regarding treatment**	• I suffered hellishly as a result of using one anticancer drug, battling day after day with frequent urination and pain. To me, the treatment method was inhuman. • After my operation, when it was decided I would take anticancer drugs, I was extremely anxious about such issues as what symptoms I would experience and whether or not I would be able to bear them. • As a side effect of the anticancer drug, I always feel unwell; my whole body feels lethargic and I am easily tired. It is very difficult, and since this has been going on for more than two and a half years now, I'm becoming really fed up with the situation. • After my diagnosis I sought information on the Internet and advice from friends and acquaintances and examined my options practically with the medical institution, but in the end I went through two months of psychological instability before a treatment method was finally decided.
3-1-3	**Feelings regarding treatment that stem from prior experiences**	• The thought of a relapse and consequently having to go through tests and treatment all over again is hard to bear as my body remembers what it has already gone through. • Of all the side effects of the anticancer drugs, nausea during the night was the most difficult to endure both mentally and physically. I never want to go through that again.
3-1-4	**Feelings regarding surgery**	• Will the operation be a success? How will my condition change after the surgery? • It took 3 months from my diagnosis to my operation. I asked repeatedly that my operation be brought forward, but I was told that I had to wait my turn, and so I waited and waited. This period was the most difficult. • I suffer from after effects of having my lymph nodes removed, and I now regret consenting to their removal.
3-1-5	**Other treatment methods**	• I was distressed because there was no one I could ask (including doctors) about alternative treatments (treatments other than surgery). • When I asked my doctor about the pros and cons of certain health foods that are reportedly effective against cancer, he completely ignored me. I felt abandoned, especially since I wasn't even taking anticancer drugs at that time.
3-1-6	**Treatment policy**	• Despite being told, after undergoing breast-conserving surgery at my previous hospital, that I would have radiation treatment everyday, the policy at the hospital where I was being treated was for only 3 times per week. I am concerned that there may be problems with this policy. • After my previous doctor was transferred, medical opinions and treatment methods changed drastically. My previous doctor prescribed chemotherapy using anticancer drugs; his replacement discharged me from hospital and prescribed recuperation at home. I felt that following my second doctor's orders would amount to simply awaiting death.

3-2-1	**Undergoing tests**	• I want to be told beforehand what the purpose of the test(s) is, and also notified of the results. • I experienced chest pain in the week between cells being taken from the lesion and hearing the test results, and so I was worried that the cancer had spread. • I was always alone during my visits to the hospital for tests prior to my admittance, so it was lonely. I think it would be great if someone could accompany you at times such as this.
3-2-2	**Test results**	• I am always in a state of uncertainty, waiting to find out the results of my daily tests.

4 Palliative care

4-1-1	**Feelings regarding the period of palliative care**	• I have concerns about such things as what is going to happen as the cancer enters its final stages. Furthermore, from about when should I start being concerned about such things? Mightn't I fall into despair? • As death draws near, my greatest fear is, will I suffer? If there is going to be pain and suffering, I would prefer euthanasia (even if that would be financially expensive). • If possible I would like to die with dignity in my own home, cared for by my family. I have absolutely no need for life-prolonging treatments.
4-1-2	**Constructive preparation for death**	• In preparation for the worst, I have written a "will" with instructions regarding my funeral and assets and messages to friends and loved ones. • With the worst case scenario of death in mind, I considered what I should do about economic matters, such as my family's living expenses, our house, and my assets.
4-2-1	**Palliative care treatment**	• I am still living with a lot of suffering; is there any way to reduce the suffering even a little? • In the final stages, what will be my symptoms and what kind of treatment will I receive?
4-2-2	**Palliative care facilities**	• I wondered if I should go into a hospice in the late stages of the cancer. • I worried about the cost of being admitted to the hospice ward.

5 Notification, informed consent, second opinion

5-1-1	**Notification method**	• When I was told about the cancer, no care was taken with such details as spoken manner or timing; their attitude was so officious I couldn't believe my ears. • The date of the operation was set for two weeks ahead, even though neither the patient nor the patient's family had been told the name of the disease. The patient's condition was explained to the family only after tests began. The family experienced tremendous psychological stress because of the consequent anxiety and mistrust.
5-2-1	**Informed consent at the hospital providing treatment**	• Two years after the surgery, my arm swelled up due to lymphedema. I would have liked it to have been explained to me that this kind of thing could occur. • The surgical procedure was explained to me, but was difficult to follow because of all the technical terms, and neither I nor my family was able to ask questions. • I was told that only blood relatives could be present with me when the surgical procedure was explained; this put me in a fix as I have no blood relatives. • I want accurate, current information. I would like to be provided with precise test data on a daily basis.

5-2-2	**Informed consent at other hospitals**	- I was given a brief explanation when informed of my condition, but after that no sufficient explanation was provided regarding the therapeutic process or treatment policy. - I experienced side effects that I had not been told about, and this made me very worried about whether or not everything was alright.
5-3-1	**Second opinions at the hospital providing treatment**	- Since it was a small hospital, I was concerned that there might not be a specialist on staff to treat my condition, but I was reluctant to look elsewhere for a second opinion. - I was given a second opinion, but I was confused about how I should handle the two opinions. - Should I get a second opinion? If so, where should I go (who should I ask) for one? - My doctor seemed in a hurry to operate and so I wanted to get a second opinion, but my relationship with my doctor soured as a result.

6 Medical coordination

6-1-1	**Follow-up after completion of main treatment**	- I experience shortness of breath and tiredness as a result of the diminishing function of my heart and lungs, and I am concerned that I will eventually be unable to visit the hospital regularly for treatment.
6-2-1	**Lack of communication and information exchange in coordination of medical care**	- I received treatment at several hospitals, but I had some very unpleasant experiences concerning notification, communication, and counseling between the various hospitals and doctors involved.

7 Home care

7-1-1	**Inability to visit a hospital regularly**	- I’m concerned about what to do regarding treatment when I become too old and infirm to visit the hospital regularly. - I have a chronic heart condition and my physical strength is weakening. I’m worried about what will happen with my treatment once I become unable to visit the hospital on a regular basis.
7-1-2	**Desire for home care**	- As my children were still infants, I was concerned about being away from home and wondered whether home care might be possible.

8 Facility and equipment/access

8-1-1	**Facilities and equipment regarded as necessary**	- Just visiting the hospital for outpatient treatment provides no opportunity to communicate with other patients and the time a patient spends mulling over concerns alone increases.
8-1-2	**Inappropriate facilities or equipment**	- It really troubles me that the posters I see in the hospital give the life expectancy for cancer patients as 5 or 10 years. It makes me sad to wonder how many years I have left to live. - I worry about whether or not people will find out that I have cancer. When hospitalized, I don’t want my nameplate displayed in the corridor.
8-2-1	**Inconvenience of visiting the hospital**	- Over the two months before my cancer diagnosis, I spent about 3 hours one way getting to the hospital for each visit. Doing the trip over and over again was both mentally and physically exhausting. - I traveled to the hospital for outpatient treatment by bus; this was very taxing as the trip coincided with rush hour and I could never get a seat.

9 Relationships with medical staff (own hospital)

9-1-1	**Feelings toward doctors and nurses (own hospital)**	• The doctors and nurses are arrogant to patients and are always scowling. I'm amazed at the number of nurses that know absolutely nothing when I ask them about the medicine I'm taking. • I want to change hospitals, but my doctor is intimidating and I'm afraid he won't give my medical records to the hospital I transfer to and am anxious about his attitude changing after I make my request. At times he has been emotional and used harsh language and so I'm afraid to say anything. • When my breast cancer was diagnosed, I requested that they remove the entire breast, but they convinced me that preservation would be possible as the cancer was in the early stages. As a result, I had to undergo repeat surgery, and after that my wound became infected. I regretted listening to them and for a while was unable to trust doctors. • While in hospital, I didn't know how I should interact with the doctors and nurses, and so I ended up obsessing over everything to the extent that I couldn't sleep. I also felt stifled as I wanted to go outside.
9-1-2	**Difficulties in communicating with medical staff**	• Whenever I ask my doctor about after effects, perhaps it's because he's so busy all the time, but he does not take my concerns seriously and doesn't listen to my questions. • Each time I go to the hospital or have a test there are lots of things I want to ask my doctor, but I'm afraid to ask, yet not asking also makes me anxious. In this way, days pass while I think about whether to ask my questions or not. ・ The length of time between examinations has gradually grown (from once every 3 months to once every 6 months), and I feel a little anxious as I have less opportunities to talk to my doctor about my current condition. ・ Since I have a hearing impairment, I have difficulty communicating with the doctors and nurses.
9-1-3	**Causes of difficulties in communication with medical staff**	• I have to say the same thing over and over again to several doctors (3-4) and nurses. Also, there is never an opportunity for my doctor and me to sit down and have a good talk, and this irritates me at times. • I desire relief for both my body and spirit when I go to the hospital for tests ー spiritual care given the same emphasis as testing, you could say. I would like to see psychological care (counseling) included in the treatment. • While I was in hospital, I was able to talk to the nurses about various concerns, but once I was discharged I had no one with medical knowledge nearby, with the result that I went through a period of psychological instability.
9-1-4	**Medical malpractice**	• The large number of medical malpractice cases reported in the news worries me.
9-2-1	**Feelings toward the medical institution (own hospital)**	• After I was transferred, I went to the hospital where I had an appointment but the doctor was no longer there and a nurse just said to me, "The doctor's busy". • The radiologist told me that it shouldn't have been necessary for everything to be removed as these days there are many treatment methods available. Why didn't my surgeon consult with the radiologist and decide on a treatment policy before my operation? • Treatment was divided up into separate specialized fields, one for each organ, and this made me anxious as there was no one monitoring my overall condition.

10 Relationships with medical staff (other hospital)

10-1-1	**Feelings toward doctors and nurses (other hospitals)**	• Without proper tests (only a manual examination), I was diagnosed with cancer, my breast was removed, and they went so far as to tell me my chances for survival, even though I hadn't asked. The technician kept laughing while he was conducting my tests, and you could hear the ringing of mobile phones inside the hospital. The doctors, technicians, and even the nurses were absolutely dreadful. • I had an MRI scan once every 3 months, and the tumor marker started appearing in a high position. At that point, the doctor said, "We've been looking all the time at your stomach, maybe there's a chance the cancer has spread to your lungs". The doctor's words made me very uneasy.
10-1-2	**Feelings toward medical staff other than doctors and nurses (other hospitals)**	• When I got my prescription filled at a pharmacy outside the hospital, I was clearly told, "This is an anticancer drug". Although up until that point I had lived life energetically and enthusiastically, I became more and more melancholy.
10-2-1	**Tests, diagnosis, and treatment at other hospitals**	• At the regular city-sponsored checkup one year previously, I was told further examination was required and so was tested twice at a hospital using an intestinal camera and barium, but no abnormalities were found either then or in gynecological tests. I left it at that for a year, not realizing that the source of the problem was my urine test, and I'm worried that the cancer may have progressed because of this oversight.
10-2-2	**Examination for treatment of conditions other than cancer**	• I want to have tests performed on another organ at a private hospital, but am reluctant to go as I would now have to write "cancer" in my medical history. • When I should see a doctor for another illness, I don't have the courage to go to another hospital, even if it's close by, and so there are times when I just put up with it instead because I don't want anyone seeing my surgical scar.

11 Symptoms, side effects and after effects

11-1-1	**Symptoms of side effects of anticancer drugs**	• I panicked when my hair began to fall out in next to no time as a side effect of the anticancer drugs. Even though there are differences between individuals, I was mentally unprepared and stunned when it happened to me. • As side effect of the anticancer drugs, I got pins and needles in my legs and feet. I felt cold from my ankles to my toes and my body felt wobbly. It was difficult to bear. • My nails have become more and more purple and my skin is becoming reddish-black. Insect bites and small injuries leave red marks, and blemishes have increased. All this has made me feel miserable.
11-1-2	**Continuation of side effects of anticancer drugs**	• Numbness in my hands has decreased, but numbness in both feet reaches as far as my arches. I worry about how many years it will be before this numbness goes away, or whether I will perhaps become unable to walk sometime in the future.
11-1-3	**Symptoms of side effects of irradiation therapy**	• When undergoing irradiation therapy, I suffered every day with nausea and lack of appetite. • After irradiation therapy, my body feels weak. I am plagued by high temperatures, with fevers preventing me from going to work for 3-4 days. • As I have Radioactive Pneumonia, I lose my breath quickly and have a cough.

11-1-4	**After effects of irradiation therapy**	• Because of the irradiation therapy, my lips are even now extremely dry and I’m always thirsty. • I don’t secrete saliva, so at night the inside of my mouth is so dry I can’t sleep. • I don’t secrete saliva, and so my throat is so painful it is difficult to eat. • Because of the radiation, I have developed cataracts and glaucoma and so have difficulty seeing and sometimes experience pain. I also get nose bleeds. • As side effects, I am unable to secrete saliva and have no taste sensation. The greatest problem at the moment is that everything I eat tastes the same. • As a side effect of the radiation I have no sensation in my tongue and no appetite, I’ve lost weight, and my back and leg joints have become painful. I can’t sleep well at night, and I’m worried about whether the pain will continue or spread.
11-1-5	**After effects of surgery**	• As a result of breathing difficulties (after my lung operation), I have difficulty conversing and walking. • As the excision was large, I have to adjust the shape when putting on tops, which makes me perspire a lot and causes me lots of trouble. • After the operation my legs were dreadfully swollen and my head continually felt heavy, as if it were full of gas. I asked the doctor about this, but he said he didn’t have an answer, which makes me anxious. • I am receiving outpatient treatment and undergoing rehabilitation for diabetes complications and a vitamin deficiency (after effects of the surgery). • Parts of my left leg (bone, skin) were transplanted into my mouth, and I am distressed by the hair that has consequently started to grow in my oral cavity.
11-1-6	**Symptoms arising from urination problems**	• Frequent urination (1-2 hours). Even now, two months after the operation, there is 20g-30g of urine leakage every day. • It took a long time before I could urinate properly, and I lost confidence for a time. There are two tubes in my abdomen to drain lymph fluid, and I am extremely anxious about removing the tubes as the amount of drainage is decreasing very slowly.
11-1-7	**Impact of urination problems on daily life**	• As I was unable to urinate properly, I received instruction on self-catheterization and measured residual urine, but even now I cannot urinate completely and having to withdraw urine numerous times in a day is very difficult. Also, measuring and recording residual urine each time is inconvenient. • I want to visit my daughter, who works a long distance away, but as I suffer from urination problems and am incontinent, I am unable to go out for long periods of time or stay overnight.
11-1-8	**Symptoms arising from dyschezia**	• I do not have daily bowel movements. When I don’t have a bowel movement for more than 20 days, sometimes even a month, I get extremely worried, and the pain and discomfort also make me anxious. Laxatives have very little effect, and I wonder how long this situation is going to last. • I had bowel movements more than 10 times a day for several days in a row. There was not enough time to get to the toilet and I would frequently leak before I got there, so about 6 months after the operation I started using adult diapers, but I was concerned that I would never return to normal.

11-1-9	**Impact of dyschezia on daily life**	• When my bowel movements were like diarrhea I couldn't get to the toilet in time and was very upset at soiling my clothes. At such times I change into paper underpants, but I need more time to learn to recognize the warning signs. • Due to a total gastrotomy, I frequently experience watery diarrhea (about once a week). • After my first operation, as most of my rectum had been removed, I would defecate as soon as I sensed the need to have a bowel movement. When I considered that I would have to wear adult nappies always if things didn't change, I was unable to leave the house for about a year.
11-1-10	**Coping with a colostomy**	• Now I have a cleansing enema twice a week. It takes about an hour and is very unpleasant. • At the time of my third operation, the positioning of the stoma was different and uneven, and it is difficult to attach the necessary equipment. The equipment also comes away easily, causing problems. • As I have Parkinson's disease, my hands shake and I cannot change the pouch by myself. It might be possible if I had nursing care. • I now have a stoma, so first of all finding a pouch that suited me was very difficult. • Since I use a stoma, I have no idea when I am going to have a bowel movement, and also the air filter gets clogged.
11-1-11	**Symptoms arising from a colostomy**	• With the stoma, my skin feels like its being pulled and the area around the stoma is painful. • The outside and inside of the opening to the stoma are always painful. • The skin area where the equipment is attached is rough and painful. When I'm not going out, I press down on it with a "cup". Is there any way to prevent the skin becoming rough?
11-1-12	**Stress arising from a colostomy**	• I was given a colostomy; this was psychologically difficult because of the way the bowels are emptied and the skin around the colostomy (the pouch slips off easily in the summer months) is irritated. • Since I had a colostomy, I have experienced many inconveniences in my daily life and stress builds up. • My dilemma is that I have to spend the rest of my life with a colostomy. • Because I was given a temporary artificial anus, on top of being troubled by excretion with the colostomy, I worried about when, or if, the temporary anus could be retrieved (removed).
11-1-13	**Impact of a colostomy on daily life**	• The most difficult thing was trying to wash my hair in the bath and handle the stoma. I had a lot of trouble because I was not properly shown how to use and care for the stoma and its equipment in the hospital. • In my work I have to deliver cases of wine and beer and, particularly in summer, the stoma bag comes off. It will come off 2-3 times in a day, and whenever this happens, my clothes are soaked and I throw them away so that my wife doesn't see them. • Because I have a colostomy, I'm nervous about going to hot springs or other places where there are a lot of people, and so I go out as little as possible. • I am careful to not pass wind when I am out in public. Depending on the type of food I have eaten, I have had trouble with diarrhea and flatulence. • Is there any way to eliminate or consciously reduce the sound of wind when it's being passed?

11-1-14	**Future colostomy management**	• When I grow old and need nursing care myself, I'm sure the person caring for me will dislike it, especially handling the colostomy equipment. • I worry about the future as it is difficult for me to change the colostomy bags by myself and I must rely entirely on my wife for help.
11-1-15	**Symptoms arising from lymphedema**	• Swelling (puffiness) of the upper limbs in the affected area becomes severe and I cannot raise my arm. • When I get tired, it's as if my lymph nodes are cramping up and my shoulders feel stiff. • Directly after surgery, I was swollen and felt stiff from the top of my leg down. Now I particularly feel pain from my ankle down, especially in my toes. • It's been one and a half years, but I still can't move my left arm as freely as I would like and I experience such symptoms as lethargy, swelling, and pain in my left arm. • I returned to work after the operation and my left leg was swollen for a time, growing quite big, and now I can't walk or do anything without the swelling intensifying.
11-1-16	**Impact of lymphedema on daily life**	• Because I developed lymphedema, I experienced some inconvenience in my daily life and it was difficult both physically and mentally. • I can't wear skirts; I can't wear shoes; my legs are different sizes. • My left leg is swollen, numb, and weak, and I cannot carry out household chores and my work to my satisfaction. • The swelling in my leg grew increasingly worse and I was diagnosed with edema, but then told that there was no treatment available. I began to be absent from work on a regular basis and eventually had to quit. • Two years ago I had an infection and had to be hospitalized; there I was told I had a phlegmone. This year I had another infection. I'm afraid to go out in the mornings and evenings.
11-1-17	**Impact of losing one's voice on daily life**	• After I was discharged from hospital, a voice generator was implanted and the generator is replaced every 3 to 4 weeks, but during those 3-4 weeks the generator has dislodged (twice), causing me great inconvenience. When this happens I have to be rushed to the hospital by ambulance, and so I am always anxious. • As I have a hole in my throat, I have difficulty taking a bath (particularly difficult in winter). • I can't answer the telephone. • I had laryngoplasty and experienced difficulties because I cannot speak as I would like. Mucous gets clogged in the hole and so I have to get my wife to clean it out twice a day. I worry about what will happen when my wife is no longer there or when I grow old.
11-1-18	**Impact of losing one's voice on social activity**	• I was no longer able to speak as a parent to my unmarried children in my own voice, and losing my voice through surgery made returning to work difficult. • Since vocalization using an amp recorder is uncommon, other people sometimes stare at me oddly when I'm in public. • My greatest problem is being unable to communicate. I feel as if I'm being discriminated against when people don't speak to me at first.

11-1-19	**Communication difficulties resulting from the loss of one's voice**	• I can't communicate with people as I would like to; I can't buy or order meals to my satisfaction. • As I can't vocalize to my satisfaction, I cannot communicate with numerous people simultaneously. • Inability to produce speech (I use an aid but speech production is insufficient.) • Since voice production requires quite a bit of physical strength, I am no longer able to communicate sufficiently, both at home and in society. • Conversations don't go as intended. Although I can make myself understood to a certain extent with my family (currently I use the Amatsu method of vocalization to converse), I have difficulty communicating effectively with people in the outside world. I had prepared myself for this, but still it is frustrating and annoying and I often become irritated.
11-1-20	**Concerns in daily life arising from a gastrotomy**	• Reverse flow and diarrhea occurring in the middle of the night. • Because of the gastrotomy, I had no appetite and soon felt full even when I could eat. Sometimes I felt constricted, and it was extremely difficult to have to prepare meals when I felt no pleasure in eating, the Number 1 basic. • I was confused about meals and what I should eat. I have no idea what I can eat or when I can start.
11-1-21	**Impact of a gastrotomy**	• Perhaps because my muscles have not recovered, I have great difficulty standing up with my back straight and so stand and walk stooped forward. When I walk, it's easiest if I use a cane. • As my stomach was reduced to one third, I lost 10 kilograms and my strength deteriorated. • For months my stomach felt stretched and a little painful after meals. • An operation to remove my stomach, gallbladder, and spleen was performed; I was troubled in the afternoons by an intermittent reverse flow of bile. • Feeling bloated (excessive passing of wind). I couldn't eat to my satisfaction.
11-1-22	**Impact of a gastrotomy on eating**	• Since a third of my stomach was removed, I was very concerned about how I should maintain a good nutritional supply. Even after going and asking people with similar experiences in my neighborhood and attempting my own research, I was still concerned. • When I eat, my stomach bloats and I can't eat to my satisfaction. I wonder about whether or not I will ever be able to eat normally again. • My stomach hurts when I eat. Pain is the norm, and so when it doesn't hurt I feel elated. It doesn't hurt if I don't eat, but then I get hungry. I cry when I think about how long this lifestyle is going to continue. • Meals don't proceed smoothly; food gets caught in my chest and takes time to go down. I am 15 kilograms lighter than when I was well and am anxious to gradually gain back some weight. • I don't feel hungry and have no appetite. • I don't know how I should eat; even if I chew slowly, I experience dumping symptoms. Mealtimes are frightening. • About 3 months after the operation, I began to feel constricted whenever I ate, as if my missing stomach were being squeezed. Food also gets caught in my throat and I vomit. Every day, meals are frightening. There are many things I would like to eat, but I can't eat them because eating is so unpleasant. It's frustrating. • Since my stomach was removed, my eating habits have changed 180 degrees; it doesn't matter what I eat, nothing tastes delicious. Before, I particularly enjoyed fish and meat, but since the operation I have

		absolutely no appetite for them. • I experience sudden stomach pain and diarrhea after meals about 2-3 times a week, and because of this I feel uneasy about eating out. Dinner with business colleagues or friends has become less frequent, and social relationships have deteriorated.
11-1-23	**Symptoms arising from ileus (intestinal obstruction)**	• Several times a year I experience ileus; I cannot express the pain and suffering I experience at these times. I now pay careful attention to my bowel movements and avoid eating to excess. • I sometimes experience ileus, causing me to vomit and suffer intestinal pain.
11-1-24	**Impact of ileus (intestinal obstruction) on daily life**	• I frequently experience ileus, and each time I have to go in and out of hospital. • I experienced ileus as a complication, and it occurred over and over again. I worried about work and became mildly depressed.
11-1-25	**Symptoms arising from changes in hormone balance**	• Because my prostate was removed, my hormones have become imbalanced and my body will sometimes suddenly lose its ability to regulate its temperature. • After hormone therapy, my physical condition changed in several ways, such as my weight ballooning rapidly and my becoming tired easily. • I’m frightened that I’ll get fat if things continue as they are. I think it’s the medication that’s making me gain weight. • My chest puffed up as a side effect of the medication (Casodex). • Heavy-headedness, stiff shoulders, joint pain (lower back, elbows, knees, wrists, fingers, etc.), heat due to high body temperature, perspiration, unpleasant vaginal discharge, and so on: taking my medication is terrible as it seems to worsen my physical condition. • My periods continue for more that 3 weeks, and the time between periods gets longer or shorter. • Pain in my bones, lower back, and knees: these seem like side effects, but sometimes perspiration pours out of me. Is there anything I should be careful about? • Probably as a side effect of taking hormones for a year, my eyesight seems to have deteriorated a little.
11-1-26	**Impact of changes in hormone balance on daily life**	• I am currently undergoing hormone therapy and am inconvenienced by the side effects of the medication. The area around my eyes feels itchy, there’s a burning sensation in the crotch area, body soap stings when I have a bath, and I feel itchy. I was examined by a gynecologist and told that my membranes had thinned. • I experience hot flushes every 2-3 weeks. Since they can happen anywhere, anytime, sometimes in the office I have to I work as I wipe off the perspiration. When I’m asleep at night I usually wake up on the first or second flush and can’t get back to sleep until they settle down. As we go into summer, particularly unpleasant days will continue. • Due to perspiration and flushes, I’m never able to sleep well at night.
11-1-27	**Symptoms arising from sexual dysfunction**	• This doesn’t constitute a major worry, but on the topic of desire, I suffer erectile dysfunction. • I have lost my sexual desire and intercourse is impossible. • I feel dissatisfied and incapacitated at being no longer able to function as a man as my nerves were severed. • At the same time I was told I had lost my ability to function as a man, I was also told that sexual activity would be impossible.

11-1-30	**Use of an artificial urinary bladder**	• As we are an elderly couple, my biggest worry is how to replace the stoma in future. • There are two bags attached, one for feces and one for urine. What with having to deal with these as well as the fact that my surgical scar has still not healed, the blood drainage tube cannot yet be removed, bandages have to be changed 2-3 times per day, and there seems to be something else on my lung, I am now wondering if it's worth living.
11-1-31	**Symptoms arising from use of an artificial urinary bladder**	• The skin surrounding the area on my stomach where the urine comes out gets red and becomes prickly or itchy if the gauze gets wet. This doesn't clear up even if I rub ointment on the area. • When you have an artificial anus or bladder, as long as you live you continue to experience itchiness, pain, inconvenience and anxiety that is unimaginable to others.
11-1-32	**Stress arising from use of an artificial urinary bladder**	• Since I was not accustomed to using it, I initially had numerous bad experiences and much trouble, getting irritated and spilling everything halfway through.
11-1-33	**Impact of use of an artificial urinary bladder on daily life**	• It's smelly because the smell of urine comes out of the hole in my stomach. I resign myself by remembering that it's an illness, but other people must think it's terrible. • An artificial bladder isn't noticeable from the outside, but urine is released at very short intervals, about 30 minutes to an hour, making it very inconvenient to travel any distance. Of course, when I do travel longer distances I use a pad (to absorb urine). • When I go out, I can't easily wash my stoma in public toilets when there are other people around. • Even if I go to heath centers or hot spring areas, there are few facilities for disabled people, and so I tend to stay away from hot springs and hotels.
11-1-34	**Effects of surgery on everyday life**	• I couldn't talk or eat properly after surgery, which was very unpleasant. After one year of man-to-man training in eating and speaking with the physician in charge I slowly recovered. I am most grateful to the doctor. • I can't eat properly. Sometimes I suffer from gastric juices, saliva and burping, and don't feel like eating. (This improves greatly with medication.) • It's very unpleasant to lose one's sense of smell and not be able to detect any odors. • I had a fluid discharge straight after leaving hospital, and received emergency treatment. They said everything was OK, but it took a long time to be able to bath properly. • It took a year for the scar to dry out. I disinfected it every day at home after leaving hospital, but this was a terrible business. • When I'm in a car the seatbelt is sometimes so painful I can't put it on. When I explained this to a policeman who stopped me, I was told to get a certificate. But the hospital said that they couldn't actually write that I didn't "have to use a safety belt", so I don't know what to do.
11-1-35	**Effects on sexual acts**	• When I masturbate I reach orgasm but ejaculate urine instead of sperm. I'm worried about the effect on my body.

11-2-1	**Continued symptoms**	• I get dizzy and out of breath after walking a few steps. • Movement became exhausting because of side effects and having pleural fluid and fluid in both lungs removed. • I developed a keloid which prickled several times a day, and sometimes sent me into sudden agony. • Maybe it's a side effect of the intravenous anticancer drugs I am taking, but my whole body feels listless, my hands and feet are cold, and I keep getting diarrhea or constipation. • I've got a ringing in my ears, I can't sleep, and my muscles hurt. I have had three operations and irradiation on my neck, where the nerves are concentrated, which have damaged my command nerves and left me sleepless. I am also reliant on medicine to urinate of defecate. • I get a temperature of around 39 degrees every day at lunch time. It goes back to normal by about 3pm if I take an antipyretic. This has been going on for two weeks. • I used a nephrostomy tube for 7 months, and was very concerned about having it removed. • I contracted shingles six months after my cancer surgery, and they still hurt. • After the transplant I suffered from several infections, interstitial pneumonia and other complications. • The side effects during and after treatment. I have no mucus. It's difficult to eat, it hurts to open my eyes. I developed glaucoma in both eyes. My work (in administration) has become even more difficult to do. My body is stiff because of atrophy. I can't move very well. • MRSA bacteria entered my stomach cancer surgery wound, and although I go to get it disinfected every day, the wound won't heal. • I'm taking Nolvadex, the antiestrogen. My liver isn't functioning properly and I was told that it was probably fatty. I'm worried about getting cirrhosis of the liver. • I was taking anticancer drugs, but they damaged my liver, so I've stopped taking them. I'm worried now because despite stopping the medicine my liver isn't getting any better. • I have a problem with my left kidney, which is malfunctioning. I sometimes worry about whether or not it's going to work properly.
11-2-3	**Impact on everyday life of other side effects**	• My gallbladder was also operated on. Since then I have not been able to eat the sort of food I used to. When I eat anything oily I get heartburn, even the smell of spinach and pine needles turns me off now. Meals are my biggest anxiety. • I'll have to eat liquid food for the rest of my life. Eating is a sort of battle with stress. • My sense of taste and smell haven't come back, so I don't cook much now, and tend to eat out more. • When I eat things get caught in my throat and I have terrible coughing fits, and sometimes I can't breathe properly. I worry that I will never get my breath back. • I felt dreadful after surgery. I couldn't sleep because of the numbness, and can only sleep now with sleeping pills. • I get tired easily and my back hurts after driving for a couple of hours. • I'm losing my appetite, and my morning stroll is becoming increasingly difficult.

11-2-4	**Physical symptoms accompanying cancer**	• It's terrible because I just can't stop coughing due to pleural fluid. • My right jaw and the right side of my face started to hurt, then I suddenly realized that the right side of the inside of my mouth had dissolved. The pain runs right up my head; spending my waking hours as if there is a bowl on my head is unpleasant. My right jaw started to rot and then became necrotic, and I was told there was nothing that could be done about it. • When I started to be unable to sleep on my side because of a build-up of abdominal fluid the surgical scar split and the fluid started to pour out of my vagina. At least it didn't hurt, but I became so depressed wondering when it would stop all I could think about was escaping from the hospital or killing myself. • I have hydrophrenosis in one of my kidneys. I am worried about finding a suitable medicine to treat it. • After ignoring the disease the cancer has spread to my bones, lungs and bone marrow. I can't produce blood and had a three liter blood transfusion; I became worried, terrified about whether or not the after effects of the chemotherapy and the clinical trial, tetanus and breathing difficulties, would get better.
11-2-5	**Symptoms caused by diseases other than cancer**	• I'm worried about the link between the ongoing complaints I have: back pains, glaucoma and chills. I want to know how I can find out information about other people who were treated. What should patients do for themselves?
11-3-1	**Life and health management after treatment**	• My body feels completely different from before I was ill. I don't understand my own constitution. • The tension of having to change my daily habits is awful. There are so many times when one is expected to have a drink, and I am surrounded by people who smoke. • Three years after surgery I still don't know what I should be careful about. • I can't go for walks or do the exercise I need because I have become diabetic again. I spend most of the time lying down, and can't lead my life in the usual way. • I can't produce enough saliva, I don't feel hungry because I have a bad sense of taste, I've lost 19 kilograms since becoming ill and can't put my weight back on. I'm worried that the lack of nutrition will effect my immune system and ability to cure myself. • I've lost so much strength just taking a shower leaves me feeling like I've been in a 100 meter race. • My body hurts every day. It's felt wrong ever since surgery, and I am worried about the scar. Worrying about whether or not it will ever go back to normal is making me prone to mental exhaustion and effecting my concentration at work • The rehabilitation after surgery was unpleasant.
11-3-2	**The difference between life before the illness and now**	• My radiotherapy finished and I left hospital, but I can't do any housework and I have to lie down after the slightest exertion. I can't carry things and walk at the same time. • My body still doesn't feel right over a year after the operation. Everyday all the things that effect my daily life and eating habits fill me with anxiety about whether or not my body will ever go back to normal. • My quality of life has dropped because I can't recover the vigor I had before my illness.

12 Anxiety and other mental problems

12-1-1	**Anxiety over spreading or recurrence**	• I thought I will have to spend the rest of my life living in fear of the words “spread” and “recur • When I was told it had spread, I couldn’t talk to my family when I wondered how long I had left to live. I suffered mentally and physically. • I thought I had been cured after my first operation; being told it had spread was the worst and saddest moment.
12-1-2	**Vague feeling of anxiety about the future**	• I was shocked to lose my voice after my throat cancer operation. • I was worried about what sort of impact a stoma would have on my daily life after being told I had to have one. • I was diagnosed with cancer and had an operation, but was worried about whether or not it would be successful, and my body would get back to normal. • I was worried about how much longer I would live, and how long the treatment would take. • I was worried about whether or not the treatment would go well and I would live a little longer, and whether or not I would be cured. • I was worried about side effects of anticancer drugs (vomiting, hair loss etc). • I’m at a stage when my children’s education is costing money so the expense of treatment was a big worry. • What would happen to me? I couldn’t visualize a blueprint for my future. • I wanted to know exactly how my symptoms would change, regardless of whether I got better or worse. • I was anxious about just how far the cancer had advanced. • I was unmarried, and became worried about every getting married. • I was worried about having a restricted diet after being told I had stomach cancer. • I was worried that it would recur even after my operation, and that I wouldn’t be able to lead the same sort of life again.
12-1-3	**Changes in relationships with close family after cancer**	• I worried about whether we would be able to stay married, or would it be better to get divorced. • As it was a women’s disease I wondered if I should get married, and how I could explain about it to him.
12-2-1	**Perception of death**	• I started worrying about death as soon as I was told I had cancer. • I was anxious the whole time, just wondering how many years more I could live. • When I was diagnosed I thought only that cancer equals death, my mind just went completely blank. • I kept thinking when and how I would die. • I was reminded of my friend’s death from cancer: I was worried that I would have to die in pain like him. I went through a feeling of terror of death after the doctor told me they would have to operate straight away or it would be too late.
12-2-2	**Perception of cancer**	• I felt I had cancer when the doctor told me he was going to give me an anticancer drug injection. • I am very nervous about recurrence of the disease, and start to think the worst whenever I get a pain. • Going into hospital and seeing the state of the other people being treated made me imagine myself ending up like them, which scared me.

12-3-1	**Mental panic and a loss of hope**	• I turned white as a sheet, felt totally helpless. • I felt like the sky was falling, the shock was so great. • I hadn’t experienced any symptoms, I couldn’t believe it, there must be some mistake, I felt. • The day I was diagnosed with cancer, everything went black, all power drained from my body, I felt totally helpless. • Hearing the name of the disease was totally unexpected. I felt as if my comfortable, happy life was ripped away. • I wondered why me, why did I have this disease. • I simply couldn’t understand; it was as if I had lost myself. • The pain was unspeakable. “Are there no gods or Buddhas?” I said to myself. • The shock of being diagnosed with cancer was so great that I couldn’t work and couldn’t sleep. Every day was like this. • I felt so alone, as if I alone had been put in the category “people with cancer”. • I didn’t want to accept the fact that I had cancer. • I was told that it was still at only the initial stage, but I worried if it wasn’t already spreading, if things weren’t really much worse. • “I’m dying”, I thought, I was filled with terror. • I had noticed the symptoms but hadn’t moved quickly enough to get a check-up. I regretted that. • I had annual physical check-up and was careful about my diet. It was really upsetting being diagnosed with cancer.
12-3-2	**Continuous psychological anxiety**	• It’s over, I thought. I feel anxious every day. • Because I believed that cancer is an incurable disease, I was overwhelmed and felt like my life was over. • I worried that when it came to cancer I had moved to slowly. I live every day afraid of dying; I am always tense and can never settle down. • Now my life is over, I was filled with anxiety and fear and lost my will to live. • Even though I had chemotherapy shots, the cancer continued to spread. The treatment didn’t seem to be effective. • After I was diagnosed with cancer, my head was filled with thoughts of death. I was irritable. I was constantly babbling. • For two years after the operation, I had no appetite at all. I couldn’t taste anything, so meals were extremely painful. I wanted to die. • Since I didn’t know anything concrete about cancer, I was extremely anxious. I worried about what I ought to do. • After I became sick, I started drinking.
12-4-1	**Depression caused by social reasons**	• Since I could not longer work, I was worried about how to pay off my home loan and medical bills. I blamed myself and became depressed. • The economic consequences and fear that this would be an obstacle for the children. I became depressed. • I panicked and needed psychotherapy because of the huge stress from concern about returning to work.
12-4-2	**Depression caused by feeling of hopelessness about the future**	• I was afraid that as the pain continued, the “me” I know would disappear. It seemed like it might be better to die.
12-4-3	**Depression caused by physical reasons**	• When symptoms of cancer appeared for two years running, I panicked and became depressed.

13 Way of living, reasons for living, set of values

13-1-1	**Feelings of meaninglessness**	• Cut off from the ties that make up a human life. Nothing more to say.
13-1-2	**Life and death**	• Wanted to take it easy but also wanted to survive. • Anxious about the end, but can’t find a reason to go on living. • Being diagnosed with cancer brought home the reality of death. I wondered if the life I lived so far had been a good one. • Constantly starting over again, with the weakened body becoming weaker still. Instead of dying in this miserable way, I would rather it be sudden, just suddenly falling apart.
13-2-1	**Approach to life after having suffered from cancer**	• For a long time my spirit was racked by the question what I could do to stop the cancer myself. • I worried that I would have to live with cancer for the rest of my life. • I worried that even if my life were saved I would still need nursing care and whether I would still be able to participate actively in society. • How could I maintain a positive attitude? • I didn’t know what to do with no future to look forward to and no reason for living.
13-3-1	**External physical changes**	• After my mastectomy, I could no longer go to hot springs or public baths without people staring at me. I could no longer enjoy those pleasures. • Because of a neurotumor on my nose, I was left with surgical scars on my face and head. Also, following radiation treatment, my skin didn’t regenerate. I was left looking awful. • Because my breast was completely removed, sweaters no longer fit properly. Brassieres didn’t look the same on both sides. Summer was especially bad. • The doctor told me that chemotherapy would cause my hair to fall out. Having no hair and no eyelashes would totally change my appearance. That was hard, I thought. • After being discharged from the hospital, I didn’t want my husband touching the scar from the (breast cancer) operation. • The chemotherapy used as a supplementary treatment totally changed my appearance (eyelashes, nails changed shape). I no longer wanted to see people. Having things to do that made me go out was stressful. • Because chemotherapy was used as a supplementary treatment, I had to wear a wig. It bothered me so much that I went out only fifty percent of the amount I used to. • Because I was operated on for breast cancer, I had to show my breasts to many doctors. That was tough.
13-3-2	**Awareness and changes in awareness of one’s own femininity or masculinity**	• Having my breast removed made me feel that I was no longer a woman. • With my womb gone, I lost all confidence in husband-wife relationships and in myself as a woman. • I was disappointed when men disappeared from my life. • I lost both of my breasts, the symbols of femininity. My husband no longer wanted to get close to me. Good husband-wife relationships were no longer possible. • Because I was pregnant, I had to have an abortion and really regretted that. It also bothers me that I can no longer have children.

13-3-3	**Changes in one's own awareness of self**	• Being told that I had an incurable illness called cancer meant that I would be of no value to society. • When I was hospitalized I could no longer deal with myself. • If this were the end, whenever I thought about my family or plans for the future, the more I hated myself. • The physical changes after my operation and the side effects of the chemotherapy turned me into a shut-in. I blamed myself for being shut off from society and having no role to play. • I felt abandoned by society; my existence had no meaning. • Whenever I meet someone who doesn't know about my illness, I feel myself withdrawing.

14 Work and financial burdens

14-1-1	**Effects of financial burdens caused by cancer**	• So much of our home loan is still outstanding. Will we be able to pay it off? • We are in business and have borrowed from banks. I worry about how to get things organized so as not to be a burden on the family. • Now there are limitations on being able to get a home loan (credit union, life insurance).
14-1-2	**Medical expenses**	• My No. 1 worry is the high cost of medical care. • For half a year, the monthly cost of outpatient care has been 100,000 yen. I wonder how long we will have to go on paying this much. • I was never sick before, so I never bought life insurance. Now that I can't work, the economic burden is going to be huge, I fear.
14-1-3	**Financial anxieties about one's future livelihood**	• I worry and am anxious about my economic situation when I retire, how I will live, whether I will be able to retire.
14-1-4	**Reduced income as a result of cancer**	• Since I am self-employed, being hospitalized means total loss of income.
14-1-5	**Expenses towards treatments and other things not covered by insurance**	• I spend a lot on health food, so economically things are pretty tight. But it's that or not staying alive, so I do what I can. • Since lymphoma isn't covered by my health insurance, it's a big economic burden.
14-2-1	**Impact of cancer on work**	• Hearing the results of my check-up, hospitalization, operation and recuperation. The moment I heard about it, I worried about the results of having to take a long time off from work. • How much and when I have to eat is out of synch with other people, so my relationships have deteriorated. I can no longer entertain my customers the way I used to as part of my sales activities. • I had just gotten a job offer. When the physical checkup revealed that I have cancer, the job offer was withdrawn.
14-2-2	**Anxieties about going back to work or continuing work (Employers)**	• I worry about returning to my company. I can't figure out how long to take time off. I worry about the future. • I worry whether I should continue my present job, even if it means being a bother to people around me, or stop working instead. • I have to take a day off from work once a week for treatment. I wonder if I shouldn't quit avoiding making trouble at my workplace.
14-2-3	**Anxieties about going back to work or continuing work (operators of businesses and self-employed persons)**	• It seems a shame that I can no longer be involved in doing business. • From an employer's point of view, I wonder how long someone who is ill should continue to work, given the current recession.

14-2-4	**Personal relationship in the workplace**	• In my workplace, I encountered people who were irritated by my tumor. • Continuing to work while receiving chemotherapy, I was bothered by having people pay special attention to me. • It is hard for people at my workplace to understand this kind of illness.
14-2-5	**Anxieties about being fired**	• Since I am always taking time off to go to the hospital, I worry about being fired and losing my job. • I was fired because I could no longer work overtime.

15 Relationships with family and other people

15-1-1	**Reactions from surrounding people once disease contracted**	• Although they were kind to me and concerned for me, I just wanted to scream at them to not mention cancer • Relationships have become strained with those who, since learning of my illness, have tried to coerce me into joining religions or buying dubious health foods and medicines. • I was very shocked to see people’s surprised reactions when my recovery went smoothly and I returned to my normal weight. • Friends spoke to me as though they believed they could catch the illness from me. • My friends have vanished since I contracted cancer.
15-1-2	**Dealing with friends, acquaintances and neighbors**	• I was at a loss as to how to explain to my neighbors etc. the change in my appearance (weight loss). • The most difficult part was pretending to be well so my relatives and others close-by would not know I had cancer. • I found it difficult to accept pity from those around (neighbors, friends) and did not enjoy having rumors about me circulate. • I found it difficult to judge at what point it was appropriate to talk to people about my illness or whether it was appropriate at all. • My internal struggle with not being able to tell anyone about the fear I felt about reaching my last days was agonizing. • I did not want my acquaintances to see what I looked like when I had no hair and was going in and out of hospital. • I live in a rural area so did not enjoy rumors being circulated about me and my cancer.
15-1-3	**Isolation from society**	• I live alone so am always worried that anything could happen at anytime. • I became depressed with shock and was unable to leave the house. • I am single and have no-one to talk to so was unsure about what to do. • I live alone so during hospitalizations I was unable to have normal social interactions. I felt this was a barrier to gaining information and friendship. • I was extremely distressed when I could not find anyone to be my reference for the times I was hospitalized. • I have no children so I do not know who will look after me during a bad convalescence.
15-1-4	**Impact on social life**	• I was concerned that I would not be able to work for someone like I did before getting sick. • I can not eat what or when I like and eating out is a problem, so I am unable to attend many gatherings.
15-1-5	**Anxieties regarding future social activities**	• I wonder whether I will be able to return to society and lead the lifestyle I led before I became ill. • I live alone so I am insecure about various issues including my every-day life.

15-1-6	**Relationships with local people**	- I have not informed neighbors of my illness and I am worried that when I don't attend local events people think badly of me. - I was an encumbrance on my family because involvements with the local community became too demanding.
15-1-7	**Relationships with other patients**	- Despite having a wide variety of after-effects I find it difficult to really understand what other patients with similar experiences or doctors are telling me. - I was diagnosed at a young age, so there were almost no other patients in a situation similar to mine.
15-1-8	**Increase in stress regarding society**	- I was worried about future employment and relationships. - I was refused marriage by my partner because I cannot bear children now that I have had my uterus surgically removed. - When I was told how much longer I have to live my fiancé broke off our engagement. - People ask me when I am going to have another child and they do not understand when I explain to them that I am unable to because of my illness, making me feel helpless and miserable.
15-1-9	**Information and the media**	- What sort of cancer did I develop, and what types of treatments are available? - I have been overloaded with stories of other people's experiences, a range of information, explanations of deaths of others around me, and I just do not know what to do. - I feel extreme grief whenever I see the mass media's sensationalistic treatment of celebrated personalities who have died after bouts with cancer (i.e. headlines of dying after a valiant struggle with cancer, etc.). - I read in the newspaper and other sources that the Agaricus mushroom can cause cancer to recede. Is that true? - I tried to find examples of people who were leading normal lives with cancer in books and other sources. However, I was unable to find someone with the same symptoms as myself, so I still feel anxious about whether I can survive.

15-2-1	**Relationship with spouse**	• I feel regret and apologetic toward my wife, in that I am unable to offer her help, and instead she has to take care of me. • My greatest concern is that my wife, who is in her 70s, suffers from liver and heart ailment, and knee, lower back, and shoulder pain, she takes care of the house, and then on top of that, she has to nurse me. • I feel like I have been relatively calm. My wife, however, collapsed in shock and was hospitalized. I think that has been my greatest worry. • I have been running a prep school with my husband—just the two of us. Since I have been hospitalized, my husband has had to look for a replacement instructor and do all of the work himself. I am concerned about his health. • I feel like we had been standing together at the same line, my spouse and I, and now I have taken one step backward. • I feel like there is awkwardness between my wife and I. During the course of being hospitalized for one year, my wife and I are no longer capable of conversation. It is difficult for our adopted child. • When I was diagnosed, I learned it was probably too late to hope for remission, so I am extremely worried about my wife being left alone, and I plan to ask my brothers and other family to take care of her if the results of the operation are not favorable. • If it seems that I am close to death because of the cancer, I would like to spend my final days with my family. However, I am worried that my husband will not take proper care of me (during that time). • My wife and I are an elderly couple living together. We cannot rely on our children. My wife, who also is in poor health, wears herself out doing the housework and working in the fields. Since I am unable to help her as much as I used to, I am worried about hear health. • We do not have any children, so I worry how my wife will survive in the future. • I do not want to cause difficulties for my husband. All my husband does is take care of me, sacrificing those things he would like to do for himself. I do not want to be a burden to him any more either emotionally or physically.
15-2-2	**Problems pertaining to relationship with spouse**	• As a result of my having cancer, troubles began to arise between my spouse and I regarding nursing care and the future, and we currently have divorce mediation proceedings underway. • My husband left me. He did not provide support either when I was diagnosed or when the doctor explained the situation. • My husband’s smoking has been problematic for me. I feel sad that he does not seem to consider my feelings. • Despite that this cancer is the first time I have been sick in my life, and that it is a serious illness, my husband, who has been with me for 16 years, told me “You like being sick”. Since he said that, I have been upset and thinking about divorcing him. • After the operation, I found it difficult to acknowledge the changes in my body, and it took a while before my husband was able to sleep with me again. I think he stopped thinking of me as a woman. • I’ve been in a bad temper and taking it out on my husband. • My husband has never been nice to me since we have been married. I am concerned about how he has become increasingly violent and cold toward me since I have been diagnosed with cancer.

15-2-3	**Relationship with family**	• I have been taking care of my mother, who is old, and I am worried about what will happen if I am hospitalized. • I am concerned about causing an extra burden on my family with cooking dinner and other housework while I am in the hospital undergoing treatment. • As soon as I start feeling a little sick, my family starts worrying and recommending that I see a doctor. I feel miserable at the worry I am causing them. • I had been discussing with my husband what our lives would be like after the children had grown and left the house. I want to be with them forever. I do not want to die. • I have been considerably depressed about being both an emotional as well as financial burden on my family (my daughter is doing all most all of the housework). • My youngest daughter, who lives with me, is unable to work outside of the house as much as she would like, because she is taking care of me and doing the housework. I feel sorry for her that she is going to waste the best years of her life taking care of her parent. • I had a family member who requires nursing care, and who could not be left in the house while I was away hospitalized and undergoing my operation, so this family member had to be put in a nursing care facility during the interim. However, since the day I was to be hospitalized was determined at the last minute, we were unable to do the paperwork processing for the facility, and now I am worried. • I am worried that I am nothing but a burden on my family. • I feel that somehow dying before my mother would be unfilial and feel upset. • Despite that I have my hands full with my own problems, even though I have younger brothers, since I am the wife of an only child, no one is helping me with the housework. • I have been endlessly worrying about a relapse and taking it out frequently on my family. I feel like I am unable to control my temper. • My stress has been causing me to take it out on my children, despite that I feel sorry for them the whole time. • Simply catching a common cold causes everyone around me to worry excessively about my health.

15-2-4	**Increase in stress in relationship with the family**	• After being discharged and coming home from the hospital, I have just been going crazy from differences of opinion with my mother-in-law. • My mother-in-law has been pushing my husband to take our child leave (i.e. divorce) since I was diagnosed with cancer. I feel considerable stress and worry resulting from my relationship with my husband's parents. • We are having disagreements about meals. We argue about the flavor of the food and how new ingredients are causing more time spent preparing. We also argue about how a special budget needs to be set aside for the meals, and everyone is always unhappy now. • I feel like over the past few years since my operation, my family has been helping me out less and less. • My family's response has been troubling me. Initially, they were zealous about taking care of me and helping me out. However, I feel that repeatedly becoming sick has caused them to be inured. • The economic burden I am causing is our largest expense, and my husband's salary just does not cover it. Yet, my husband still does not seem to be worried about our financial state. I am worried about how much longer we can rely on our income to cover the expenses. • Since there is no one to take care of my husband in my stead, I am exhausted and reaching my physical limit. My husband is losing his ability to stand. I am worried that I do not have enough strength to live longer than my husband. • I am at a loss from things in everyday life, like problems with my mother-in-law and preparing meals for my father-in-law. I would like to have some freedom for myself in the future. • Women feel sadness in having to think about the housework and daily living first and foremost, even after having been diagnosed with cancer. I would rather not have to think about anything else, so I could just poor every ounce of me emotionally into my treatment. • My little brother and I have matching HLA, but he refused to be a donor, and now I am worried about the possibility of a transplant. I am also concerned about my father, who seems to have no conception of my illness.
15-2-5	**Informing the family, etc.**	• My parents are advanced in age, so I have not yet mentioned being transferred to another hospital. There are all these points I have to give consideration. • I explained to my children about my illness so that they will not worry. • As soon as I was diagnosed with cancer, I was to undergo radiation treatment. It was all so sudden I was at a loss of how to tell my family, especially my husband. • When I went in for a checkup, the doctor informed me that I had a lump in my breast. Since there was no one in either my immediate or extended family history who had ever had cancer, my mind just went blank. I also felt extremely distressed at having to tell my family. • My biggest concern is ensuring that my daughter and father do not find out that I have cancer. • I do not want my parents to know about the cancer's recurrence, so I am keeping my treatment a secret.

15-2-6	**Familial concerns**	• My husband's older sister, who lives in the same housing development, is undergoing treatment for diabetes. My husband is advanced in age. I am worried about one of us becoming bedridden. • Naturally, I am concerned about myself, but also about my mother, who is elderly, and my family. • My elderly mother is currently hospitalized and undergoing treatment, so I am concerned about the future. • I am worried what will have my family if something should happen to me. I take are of all of the housework (including managing household finances). I do not think someone else could handle the housework properly.
15-2-7	**Relationship with children**	• Since my children were small (a preschooler and an infant) when I was diagnosed, so I was worried what would happen to them while I was hospitalized. I was worried about how to manage us getting along with our daily lives. • I feel like things I am able to do for my children, such as being able to attend my children's school functions or events, are gradually disappearing, which makes me feel sad. • My son skipped an exam and had been acting emotionally unbalanced, repeatedly engaging in rebellious behavior. Now, my cancer has metastasized, and I have been depressed, and he has been avoiding me. He spends the night out cavorting and comes home late. • I do not want to make my children unhappy worrying about whether they will inherit my genes and end up with the same illness. • We are a single-mother household. The facility where I leave my oldest boy limits their services one week, so I had a rough time negotiating to get them to take him for a month. I was not able to feel at ease during my hospital stay, and had to have myself discharged two weeks after my operation. • I am not sure how many years ago I became infected with hepatitis C, but I am worried that my family (my wife has hepatitis C), my children, and my grandchildren will become infected (through saliva, blood, etc.). • I have two children, and children have their childhood to live. Everyday I worry about how to lead my life so as not to impose on their childhood. • I am wearing a wig now because of the chemotherapy, so the children are conscious of my having cancer and act inhibited when they play with me. Furthermore, children I am near are very conscientious about avoiding touching my head, and I just feel exhausted. • My hair fell out as a side effect of the treatment, so now I wear a wig and do not enjoy going out or having the children visit. • When we learned my cancer was in the final stages, I asked my daughter to take care of my wife, but this has been a huge financial burden on us (my daughter currently works). • My children are small, and after I had my operation, my body was weak, and I overexerted myself holding and playing with the children.

15-2-8	**Concern about children**	• I feel overwhelmed with concern when I think about my children being left behind without me. • My daughter was supposed to take her exams, but now I am worried what will happen. I cannot die. I do not want to die. • When I was diagnosed with cancer, I had planned on watching my children grow up. Now, I am wondering if I still will be able. • We are a single-mother household, and I just cannot die and leave behind my children, who are still in elementary school. • My daughter has a disability, and I am extremely concerned about leaving her behind. • My daughter had been hospitalized with anorexia, and she does not seem to be over it yet (she gives the impression of leading a normal life right now, but her eating habits are not normal). My daughter’s eating disorder added to my own illness are both causes of worry.
15-2-9	**Anxieties about pregnancy, giving birth, and raising children**	• I thought I might like to have another child, but now I am wondering if that is a possibility. And, supposing I were to get pregnant, I wonder if my child would be normal. • I learned that I had cervical cancer when my OBGYN did a biopsy of my cervix when I was pregnant. I am concerned whether I can continue my pregnancy. • I was diagnosed with uterine cancer at the same time I became pregnant. Now I am worried whether I will be able to give birth, and even supposing that I am, it is certain that the birth will be premature, so I am worried that my child might have a hearing disorder or other form of birth defect. • I had to give my two-month old baby to my parents so that I could be hospitalized. My baby was not yet weaned, so I felt pain while I was in the hospital (both from my breasts aching and from the emotional pain of not being able to feed my child). • I was not able to undergo surgery immediately, because I was pregnant. I heard that cancer progresses quickly when during pregnancy, and I am worried that it will metastasize. • I was pregnant when I was diagnosed, so I worried about whether I should have an abortion, then I regretted having an abortion, and now I am worried if I ever will be able to have a child in the future.
15-2-11	**Disagreements with family members**	• My spouse is recommending that I take folk remedies for my cancer and refusing surgical treatment. My physician fully informed me of my choices, but now I am worried about convincing my spouse (i.e. getting my spouse to agree). • I selected the hospital myself, and I trust my physician. Provided that nothing particular arises, I would like my doctor to take care of me. However, my friends, my relatives, everyone has suddenly turned into a medical analyst, and are causing trouble for me by interfering. • I was able to make my own decisions without a problem, but now everyone (my friends, my immediate family, my relatives) are offering their own advice.

Appendix 4 Comparison with results of surveys conducted by medical institutions and patients'/patients' support groups

Question 1. At what age were you diagnosed as suffering from cancer? (By age group）

Age at diagnosis	Medical Institutions Number	(%)	Patients' Groups Number	(%)
1. 20s	81	(1.1%)	29	(4.8%)
2. 30s	334	(4.6%)	101	(16.8%)
3. 40s	986	(13.6%)	198	(32.9%)
4. 50s	1,866	(25.8%)	170	(28.2%)
5. 60s	2,293	(31.7%)	76	(12.6%)
6. 70s	1,410	(19.5%)	17	(2.8%)
7. 80s	124	(1.7%)	1	(0.2%)
8. 90s	4	(0.1%)	0	―
No response	137	(1.9%)	10	(1.7%)
Total	7,235	(100.0%)	602	(100.0%)

Question 2. What type of cancer were you diagnosed with? Please circle one type.

Body part	Medical Institutions Number	(%)	Patients' Groups Number	(%)
1. Brain	3	(0.0%)	1	(0.2%)
2. Pharynx/larynx	270	(3.7%)	1	(0.2%)
3. Lung	735	(10.2%)	14	(2.3%)
4. Esophagus	226	(3.1%)	4	(0.7%)
5. Stomach	1,018	(14.1%)	28	(4.7%)
6. Duodenum/small intestine	33	(0.5%)	2	(0.3%)
7. Colon/rectum	1,027	(14.2%)	28	(4.7%)
8. Liver	250	(3.5%)	5	(0.8%)
9. Biliary tract/gall bladder	84	(1.2%)	3	(0.5%)
10. Pancreas	97	(1.3%)	5	(0.8%)
11. Kidney/adrenal gland	70	(1.0%)	6	(1.0%)
12. Urinary bladder	118	(1.6%)	2	(0.3%)
13. Skin	28	(0.4%)	1	(0.2%)
14. Mouth/Tongue	100	(1.4%)	0	―
15. Uterus	392	(5.4%)	106	(17.6%)
16. Ovary/fallopian tube	113	(1.6%)	43	(7.1%)
17. Breast	1,663	(23.0%)	241	(40.0%)
18. Prostate	292	(4.0%)	10	(1.7%)
19. Testicle	13	(0.2%)	1	(0.2%)
20. Thyroid gland	89	(1.2%)	1	(0.2%)
21. Leukemia	93	(1.3%)	69	(11.5%)
22. Myeloma	32	(0.4%)	0	―
23. Bone	8	(0.1%)	0	―
24. Soft tissue (muscle/fat)	29	(0.4%)	1	(0.2%)
25. Lymphoma	186	(2.6%)	11	(1.8%)
26. Other	97	(1.3%)	5	(0.8%)
No response	169	(2.3%)	14	(2.3%)
Total	7,235	(100.0%)	602	(100.0%)

Question 3. Have you subsequently been told by your doctor that a recurrence or spreading of the cancer has been detected?

Recurrence/ spread	Medical Institutions Number	(%)	Patients' Groups Number	(%)
1. Yes	1,730	(23.9%)	122	(20.3%)
2. No	5,279	(73.0%)	465	(77.2%)
No response	226	(3.1%)	15	(2.5%)
Total	7,235	(100.0%)	602	(100.0%)

Supplementary question 3-1. Circle all the parts of your body in which recurrence or spreading has been detected（as many as applicable）.

	Number of respondents=1,730		Number of respondents=122	
Region of recurrence/metastasis	Medical Institutions Number	（%）	Patients' Groups Number	（%）
1. Brain/meninges	78	(4.5%)	7	(5.7%)
2 . Pharynx/larynx	43	(2.5%)	2	(1.6%)
3. Lung/pleura	470	(27.2%)	28	(23.0%)
4. Esophagus	24	(1.4%)	0	―
5. Stomach	85	(4.9%)	3	(2.5%)
6. Duodenum/Small intestine	20	(1.2%)	1	(0.8%)
7. Colon/rectum	140	(8.1%)	9	(7.4%)
8. Liver	437	(25.3%)	18	(14.8%)
9. Biliary tract/gall bladder	15	(0.9%)	1	(0.8%)
10. Pancreas	25	(1.4%)	1	(0.8%)
11. Kidney/adrenal gland	40	(2.3%)	2	(1.6%)
12. Urinary bladder	68	(3.9%)	0	―
13. Skin	23	(1.3%)	4	(3.3%)
14. Mouth/tongue	11	(0.6%)	0	―
15. Uterus	29	(1.7%)	2	(1.6%)
16. Ovary/fallopian tube	31	(1.8%)	5	(4.1%)
17. Breast	103	(6.0%)	17	(13.9%)
18. Prostate	40	(2.3%)	1	(0.8%)
19. Testicle	0	―	0	―
20. Thyroid gland	17	(1.0%)	1	(0.8%)
21. Bone marrow	22	(1.3%)	10	(8.2%)
22. Lymph node (gland)	401	(23.2%)	32	(26.2%)
23. Bone	249	(14.4%)	22	(18.0%)
24. Soft tissue (muscle/fat)	14	(0.8%)	1	(0.8%)
25. Spinal cord	27	(1.6%)	2	(1.6%)
26. Peritoneum	39	(2.3%)	7	(5.7%)
27. Pericardium/pericardial membrane	2	(0.1%)	0	―
28. Other	49	(2.8%)	11	(9.0%)
No response	24	(1.4%)	2	(1.6%)

Question 4. Circle whichever of the following best describes the current state of your treatment.

State of treatment	Medical Institutions		Patients' Groups	
	Number	(%)	Number	(%)
1. Undergoing continuous treatment	2,674	(37.0%)	146	(24.3%)
2. Visiting hospital for regular check-ups	4,380	(60.5%)	378	(62.8%)
3. Other	69	(1.0%)	66	(11.0%)
No response	112	(1.5%)	12	(2.0%)
Total	7,235	(100.0%)	602	(100.0%)

Question 5. Circle all of the types of treatment that you have undergone so far <u>at medical institutions</u> (as many as applicable).

	Number of respondents=7,235		Number of respondents=602	
Treatment	Medical Institutions		Patients' Groups	
	Number	(%)	Number	(%)
1. Surgery	5,520	(76.3%)	493	(81.9%)
2. Endoscopic, thoracoscopic or laparoscopic surgery	1,906	(26.3%)	62	(10.3%)
3. Drug therapy (anticancer drugs or hormone drugs etc)	4,163	(57.5%)	438	(72.8%)
4. Irradiation therapy	2,140	(29.6%)	234	(38.9%)
5. Other	82	(1.1%)	39	(6.5%)
No response	163	(2.3%)	8	(1.3%)

Question 6. Circle the statement below that most accurately describes your current lifestyle.

Daily life	Medical Institutions Number	(%)	Patients' Groups Number	(%)
1. I have no particular symptoms and can participate in social activities. I am not constrained by my illness or treatments, and I can still perform activities that I was performing before I contracted cancer.	4,037	(55.8%)	375	(62.3%)
2. I have mild symptoms. I am not always capable of performing work that requires physical effort (physical labor), but can walk and perform light and sedentary work such as housework or office work.	2,447	(33.8%)	202	(33.6%)
3. I can walk and take care of myself, but sometimes I need the help of others. I cannot perform light work, but am up and out of bed for at least half the day.	400	(5.5%)	12	(2.0%)
4. I can take care of myself to a certain extent, but often need someone's help. I am in bed for at least half the day.	187	(2.6%)	1	(0.2%)
5. I can not take care of myself and always need someone's help. I stay in bed all day.	14	(0.2%)	2	(0.3%)
No response	150	(2.1%)	10	(1.7%)
Total	7,235	(100.0%)	602	(100.0%)

Question 7. What did you become anxious about? Circle all of the answers applicable.

	Number of respondents=7,235		Number of respondents=602	
Worry/bother	Medical Institutions		Patients' Groups	
	Number	(%)	Number	(%)
1.Physical suffering including pain side-effects and after-effects	3,389	(46.8%)	381	(63.3%)
2.Psychological issues such as depression, worry or fear	3,731	(51.6%)	413	(68.6%)
3.Family/household issues such as conjugal relations or parent-child relations	2,049	(28.3%)	228	(37.9%)
4.Societal issues such as employment, position, social relations etc.	1,419	(19.6%)	189	(31.4%)
5.Relationships with medical staff	484	(6.7%)	144	(23.9%)
6.Economic issues such as income, treatment costs and savings for the future	2,543	(35.1%)	209	(34.7%)
7.Future way of life or the meaning of life	2,623	(36.3%)	326	(54.2%)
8.Other	147	(2.0%)	33	(5.5%)
No response	848	(11.7%)	25	(4.2%)

Question 8. Did you discuss the anxieties cited in question 7? Circle each of the applicable numbers for each period.

(a. Around the time of diagnosis)

Discusses anxieties or otherwise	Medical Institutions		Patients' Groups	
	Number	(%)	Number	(%)
1. Didn't want to discuss them with anybody	1,461	(20.2%)	109	(18.1%)
2. Discussed or attempted to discuss	4,585	(63.4%)	451	(74.9%)
No response	1,189	(16.4%)	42	(7.0%)
Total	7,235	(100.0%)	602	(100.0%)

Question 9. If you circled 2 (discussed or attempted to discuss) in Question 8, please indicate all of the people or institutions you discussed your anxieties with listed below (as many as applicable).

	Number of respondents=4,585		Number of respondents=451	
Worries dissipated	Medical Institutions		Patients' Groups	
	Number	(%)	Number	(%)
1. Family	2,760	(60.2%)	216	(47.9%)
2. Friends/acquaintances	995	(21.7%)	143	(31.7%)
3. Relatives	760	(16.6%)	57	(12.6%)
4. Colleague	246	(5.4%)	26	(5.8%)
5. Patient with same illness met in hospital	404	(8.8%)	83	(18.4%)
6. Patient/self-help group	22	(0.5%)	98	(21.7%)
7. One's own doctor	1,182	(25.8%)	106	(23.5%)
8. Nurse	297	(6.5%)	34	(7.5%)
9. Other people	85	(1.9%)	26	(5.8%)
a. Hospital counseling room etc.	45	(1.0%)	4	(0.9%)
b. Prefectural or municipal consultation services	24	(0.5%)	0	―
c. Other institutions	36	(0.8%)	3	(0.7%)
No response	789	(17.2%)	89	(19.7%)

Worries did not dissipate	Medical Institutions		Patients' Groups	
	Number	(%)	Number	(%)
1. Family	524	(11.4%)	55	(12.2%)
2. Friends/acquaintances	167	(3.6%)	26	(5.8%)
3. Relatives	128	(2.8%)	16	(3.5%)
4. Colleague	47	(1.0%)	7	(1.6%)
5. Patient with same illness met in hospital	44	(1.0%)	9	(2.0%)
6. Patient/self-help group	3	(0.1%)	14	(3.1%)
7. One's own doctor	131	(2.9%)	25	(5.5%)
8. Nurse	36	(0.8%)	13	(2.9%)
9. Other people	7	(0.2%)	0	―
a. Hospital counseling room etc.	8	(0.2%)	4	(0.9%)
b. Prefectural or municipal consultation services	5	(0.1%)	1	(0.2%)
c. Other institutions	6	(0.1%)	4	(0.9%)
No response	789	(17.2%)	89	(19.7%)

(a. Around the time of diagnosis)

They did not talk with me	Medical Institutions		Patients’ Groups	
	Number	(%)	Number	(%)
1. Family	5	(0.1%)	6	(1.3%)
2. Friends/acquaintances	3	(0.1%)	2	(0.4%)
3. Relatives	4	(0.1%)	0	−
4. Colleague	3	(0.1%)	2	(0.4%)
5. Patient with same illness met in hospital	0	−	1	(0.2%)
6. Patient/self-help group	0	−	0	−
7. One’s own doctor	6	(0.1%)	3	(0.7%)
8. Nurse	1	(0.0%)	2	(0.4%)
9. Other people	1	(0.0%)	0	−
a. Hospital counseling room etc.	0	−	1	(0.2%)
b. Prefectural or municipal consultation services	1	(0.0%)	1	(0.2%)
c. Other institutions	0	−	1	(0.2%)
No response	789	(17.2%)	89	(19.7%)

I could not consult them	Medical Institutions		Patients’ Groups	
	Number	(%)	Number	(%)
1. Family	15	(0.3%)	3	(0.7%)
2. Friends/acquaintances	24	(0.5%)	3	(0.7%)
3. Relatives	11	(0.2%)	4	(0.9%)
4. Colleague	4	(0.1%)	4	(0.9%)
5. Patient with same illness met in hospital	3	(0.1%)	1	(0.2%)
6. Patient/self-help group	4	(0.1%)	3	(0.7%)
7. One’s own doctor	17	(0.4%)	7	(1.6%)
8. Nurse	3	(0.1%)	2	(0.4%)
9. Other people	0	−	1	(0.2%)
a. Hospital counseling room etc.	2	(0.0%)	2	(0.4%)
b. Prefectural or municipal consultation services	3	(0.1%)	1	(0.2%)
c. Other institutions	1	(0.0%)	1	(0.2%)
No response	789	(17.2%)	89	(19.7%)

I could not find anyone to talk to	Medical Institutions Number	(%)	Patients' Groups Number	(%)
1. Family	5	(0.1%)	2	(0.4%)
2. Friends/acquaintances	3	(0.1%)	1	(0.2%)
3. Relatives	4	(0.1%)	1	(0.2%)
4. Colleague	2	(0.0%)	0	―
5. Patient with same illness met in hospital	5	(0.1%)	0	―
6. Patient/self-help group	5	(0.1%)	4	(0.9%)
7. One's own doctor	3	(0.1%)	1	(0.2%)
8. Nurse	0	―	0	―
9. Other people	3	(0.1%)	1	(0.2%)
a. Hospital counseling room etc.	2	(0.0%)	1	(0.2%)
b. Prefectural or municipal consultation services	5	(0.1%)	2	(0.4%)
c. Other institutions	4	(0.1%)	2	(0.4%)
No response	789	(17.2%)	89	(19.7%)

(b. From diagnosis until the present time)

Discusses anxieties or otherwise	Medical Institutions Number	(%)	Patients' Groups Number	(%)
1. Didn't want to discuss them with anybody	1,038	(14.3%)	61	(10.1%)
2. Discussed or attempted to discuss	3,791	(52.4%)	475	(78.9%)
No response	2,406	(33.3%)	66	(11.0%)
Total	7,235	(100.0%)	602	(100.0%)

	Number of respondents=3,791		Number of respondents=475	
Worries dissipated	Medical Institutions Number	(%)	Patients' Groups Number	(%)
1. Family	2,093	(55.2%)	186	(39.2%)
2. Friends/acquaintances	952	(25.1%)	124	(26.1%)
3. Relatives	611	(16.1%)	42	(8.8%)
4. Colleague	191	(5.0%)	21	(4.4%)
5. Patient with same illness met in hospital	746	(19.7%)	130	(27.4%)
6. Patient/self-help group	62	(1.6%)	195	(41.1%)
7. One's own doctor	1,353	(35.7%)	136	(28.6%)
8. Nurse	418	(11.0%)	53	(11.2%)
9. Other people	74	(2.0%)	28	(5.9%)
a. Hospital counseling room etc.	51	(1.3%)	14	(2.9%)
b. Prefectural or municipal consultation services	19	(0.5%)	2	(0.4%)
c. Other institutions	42	(1.1%)	9	(1.9%)
No response	693	(18.3%)	99	(20.8%)

Worries did not dissipate	Medical Institutions Number	 (%)	Patients' Groups Number	 (%)
1. Family	270	(7.1%)	26	(5.5%)
2. Friends/acquaintances	100	(2.6%)	27	(5.7%)
3. Relatives	73	(1.9%)	6	(1.3%)
4. Colleague	30	(0.8%)	5	(1.1%)
5. Patient with same illness met in hospital	61	(1.6%)	13	(2.7%)
6. Patient/self-help group	4	(0.1%)	14	(2.9%)
7. One's own doctor	136	(3.6%)	31	(6.5%)
8. Nurse	44	(1.2%)	10	(2.1%)
9. Other people	6	(0.2%)	2	(0.4%)
a. Hospital counseling room etc.	12	(0.3%)	0	—
b. Prefectural or municipal consultation services	4	(0.1%)	2	(0.4%)
c. Other institutions	9	(0.2%)	5	(1.1%)
No response	693	(18.3%)	99	(20.8%)

(b. From diagnosis until the present time)

They did not talk with me	Medical Institutions Number	 (%)	Patients' Groups Number	 (%)
1. Family	3	(0.1%)	3	(0.6%)
2. Friends/acquaintances	1	(0.0%)	1	(0.2%)
3. Relatives	3	(0.1%)	1	(0.2%)
4. Colleague	1	(0.0%)	1	(0.2%)
5. Patient with same illness met in hospital	1	(0.0%)	0	—
6. Patient/self-help group	0	—	1	(0.2%)
7. One's own doctor	5	(0.1%)	11	(2.3%)
8. Nurse	3	(0.1%)	0	—
9. Other people	1	(0.0%)	0	—
a. Hospital counseling room etc.	2	(0.1%)	0	—
b. Prefectural or municipal consultation services	0	—	1	(0.2%)
c. Other institutions	0	—	0	—
No response	693	(18.3%)	99	(20.8%)

I could not consult them	Medical Institutions Number	(%)	Patients' Groups Number	(%)
1. Family	10	(0.3%)	4	(0.8%)
2. Friends/acquaintances	15	(0.4%)	2	(0.4%)
3. Relatives	6	(0.2%)	3	(0.6%)
4. Colleague	4	(0.1%)	5	(1.1%)
5. Patient with same illness met in hospital	8	(0.2%)	2	(0.4%)
6. Patient/self-help group	8	(0.2%)	3	(0.6%)
7. One's own doctor	26	(0.7%)	7	(1.5%)
8. Nurse	8	(0.2%)	1	(0.2%)
9. Other people	1	(0.0%)	0	―
a. Hospital counseling room etc.	4	(0.1%)	5	(1.1%)
b. Prefectural or municipal consultation services	3	(0.1%)	1	(0.2%)
c. Other institutions	1	(0.0%)	0	―
No response	693	(18.3%)	99	(20.8%)

I could not find anyone to talk to	Medical Institutions Number	(%)	Patients' Groups Number	(%)
1. Family	2	(0.1%)	1	(0.2%)
2. Friends/acquaintances	2	(0.1%)	1	(0.2%)
3. Relatives	2	(0.1%)	1	(0.2%)
4. Colleague	1	(0.0%)	0	―
5. Patient with same illness met in hospital	2	(0.1%)	1	(0.2%)
6. Patient/self-help group	6	(0.2%)	2	(0.4%)
7. One's own doctor	4	(0.1%)	1	(0.2%)
8. Nurse	1	(0.0%)	1	(0.2%)
9. Other people	5	(0.1%)	1	(0.2%)
a. Hospital counseling room etc.	4	(0.1%)	1	(0.2%)
b. Prefectural or municipal consultation services	4	(0.1%)	0	―
c. Other institutions	3	(0.1%)	3	(0.6%)
No response	693	(18.3%)	99	(20.8%)

(c. Currently)

Discusses anxieties or otherwise	Medical Institutions Number	(%)	Patients' Groups Number	(%)
1. Didn't want to discuss them with anybody	1,183	(16.4%)	93	(15.4%)
2. Discussed or attempted to discuss	3,148	(43.5%)	378	(62.8%)
No response	2,904	(40.1%)	131	(21.8%)
Total	7,235	(100.0%)	602	(100.0%)

	Number of respondents=3,148		Number of respondents=378	
Worries dissipated	Medical Institutions		Patients’ Groups	
	Number	(%)	Number	(%)
1. Family	1,704	(54.1%)	136	(36.0%)
2. Friends/acquaintances	738	(23.4%)	88	(23.3%)
3. Relatives	441	(14.0%)	25	(6.6%)
4. Colleague	142	(4.5%)	14	(3.7%)
5. Patient with same illness met in hospital	496	(15.8%)	72	(19.0%)
6. Patient/self-help group	48	(1.5%)	148	(39.2%)
7. One’s own doctor	1,114	(35.4%)	100	(26.5%)
8. Nurse	237	(7.5%)	25	(6.6%)
9. Other people	68	(2.2%)	19	(5.0%)
a. Hospital counseling room etc.	33	(1.0%)	5	(1.3%)
b. Prefectural or municipal consultation services	22	(0.7%)	0	—
c. Other institutions	40	(1.3%)	9	(2.4%)
No response	605	(19.2%)	87	(23.0%)

Worries did not dissipate	Medical Institutions		Patients’ Groups	
	Number	(%)	Number	(%)
1. Family	217	(6.9%)	19	(5.0%)
2. Friends/acquaintances	80	(2.5%)	16	(4.2%)
3. Relatives	58	(1.8%)	3	(0.8%)
4. Colleague	19	(0.6%)	5	(1.3%)
5. Patient with same illness met in hospital	47	(1.5%)	9	(2.4%)
6. Patient/self-help group	3	(0.1%)	12	(3.2%)
7. One’s own doctor	110	(3.5%)	23	(6.1%)
8. Nurse	29	(0.9%)	2	(0.5%)
9. Other people	6	(0.2%)	3	(0.8%)
a. Hospital counseling room etc.	9	(0.3%)	0	—
b. Prefectural or municipal consultation services	5	(0.2%)	1	(0.3%)
c. Other institutions	10	(0.3%)	6	(1.6%)
No response	605	(19.2%)	87	(23.0%)

(c. Currently)

They did not talk with me	Medical Institutions		Patients' Groups	
	Number	(%)	Number	(%)
1. Family	3	(0.1%)	3	(0.8%)
2. Friends/acquaintances	1	(0.0%)	0	－
3. Relatives	5	(0.2%)	0	－
4. Colleague	5	(0.2%)	0	－
5. Patient with same illness met in hospital	0	－	0	－
6. Patient/self-help group	0	－	0	－
7. One's own doctor	0	－	1	(0.3%)
8. Nurse	3	(0.1%)	2	(0.5%)
9. Other people	0	－	0	－
a. Hospital counseling room etc.	1	(0.0%)	0	－
b. Prefectural or municipal consultation services	3	(0.1%)	0	－
c. Other institutions	1	(0.0%)	0	－
No response	605	(19.2%)	87	(23.0%)

I could not consult them	Medical Institutions		Patients' Groups	
	Number	(%)	Number	(%)
1. Family	15	(0.5%)	2	(0.5%)
2. Friends/acquaintances	12	(0.4%)	1	(0.3%)
3. Relatives	7	(0.2%)	1	(0.3%)
4. Colleague	3	(0.1%)	0	－
5. Patient with same illness met in hospital	4	(0.1%)	0	－
6. Patient/self-help group	5	(0.2%)	3	(0.8%)
7. One's own doctor	24	(0.8%)	7	(1.9%)
8. Nurse	6	(0.2%)	1	(0.3%)
9. Other people	0	－	0	－
a. Hospital counseling room etc.	6	(0.2%)	3	(0.8%)
b. Prefectural or municipal consultation services	3	(0.1%)	1	(0.3%)
c. Other institutions	3	(0.1%)	0	－
No response	605	(19.2%)	87	(23.0%)

I could not find anyone to talk to	Medical Institutions		Patients’ Groups	
	Number	(%)	Number	(%)
1. Family	2	(0.1%)	1	(0.3%)
2. Friends/acquaintances	2	(0.1%)	1	(0.3%)
3. Relatives	1	(0.0%)	0	－
4. Colleague	2	(0.1%)	2	(0.5%)
5. Patient with same illness met in hospital	2	(0.1%)	0	－
6. Patient/self-help group	3	(0.1%)	1	(0.3%)
7. One’s own doctor	5	(0.2%)	2	(0.5%)
8. Nurse	0	－	0	－
9. Other people	8	(0.3%)	1	(0.3%)
a. Hospital counseling room etc.	6	(0.2%)	2	(0.5%)
b. Prefectural or municipal consultation services	5	(0.2%)	0	－
c. Other institutions	7	(0.2%)	3	(0.8%)
No response	605	(19.2%)	87	(23.0%)

Question 10. What do you think is needed in order to provide some relief from the anxieties you had or have now? Write whatever you like.

Number of respondents＝7,235　Number of respondents=602

Desired assistance	Medical Institutions		Patients’ Groups	
	Number	(%)	Number	(%)
1. Relationships with medical staff	1,331	(18.4%)	138	(22.9%)
	723	(10.0%)	162	(26.9%)
2. Counseling/psychological care	380	(5.3%)	36	(6.0%)
3. Economic assistance with medical costs etc.	367	(5.1%)	103	(17.1%)
4. Supply and disclosure of information	452	(6.2%)	184	(30.6%)
5. Interaction with similar patients/patient groups	1,287	(17.8%)	145	(24.1%)
6. Decisions made with own efforts	593	(8.2%)	55	(9.1%)
7. Cooperation, understanding and support from family	173	(2.4%)	31	(5.2%)
8. Cooperation, understanding and support from friends	446	(6.2%)	68	(11.3%)
9. Demands to the administration or medical institutions	234	(3.2%)	18	(3.0%)
10.Medical progress	63	(0.9%)	7	(1.2%)
11.Religion	140	(1.9%)	14	(2.3%)
12.Work environment	38	(0.5%)	8	(1.3%)
13.Other	2,870	(39.7%)	56	(9.3%)

Question 11. Please indicate your date of birth. (By age group)

Age	Medical Institutions		Patients’ Groups	
	Number	(%)	Number	(%)
1. 20s	41	(0.6%)	4	(0.7%)
2. 30s	205	(2.8%)	53	(8.8%)
3. 40s	662	(9.1%)	140	(23.3%)
4. 50s	1,602	(22.1%)	207	(34.4%)
5. 60s	2,282	(31.5%)	113	(18.8%)
6. 70s	2,024	(28.0%)	49	(8.1%)
7. 80s	269	(3.7%)	3	(0.5%)
8. 90s	6	(0.1%)	0	―
No response	144	(2.0%)	33	(5.5%)
Total	7,235	(100.0%)	602	(100.0%)

Question 12. Please indicate your gender.

Gender	Medical Institutions		Patients’ Groups	
	Number	(%)	Number	(%)
1.Male	3,440	(47.5%)	91	(15.1%)
2.Female	3,739	(51.7%)	481	(79.9%)
No response	56	(0.8%)	30	(5.0%)
Total	7,235	(100.0%)	602	(100.0%)

Question 13. Please tell us about your family.

Question 13-1. Are you currently married? Circle the appropriate response.

Marital status	Medical Institutions		Patients’ Groups	
	Number	(%)	Number	(%)
1.Single	360	(5.0%)	69	(11.5%)
2.Married	5,808	(80.3%)	444	(73.8%)
3.Divorced/ widowed	952	(13.2%)	59	(9.8%)
No response	115	(1.6%)	30	(5.0%)
Total	7,235	(100.0%)	602	(100.0%)

Question 13-2. Do you currently live with someone? Indicate their relationship to you by circling all the appropriate responses.

	Number of respondents＝7,235		Number of respondents=602	
Co-habitants	Medical Institutions		Patients' Groups	
	Number	(%)	Number	(%)
1.Live alone	594	(8.2%)	64	(10.6%)
2.Spouse (husband or wife)	5,607	(77.5%)	433	(71.9%)
3.Father	212	(2.9%)	27	(4.5%)
4.Mother	541	(7.5%)	62	(10.3%)
5.Spouse's father	143	(2.0%)	23	(3.8%)
6.Spouse's mother	323	(4.5%)	44	(7.3%)
7.Sibling(s)	156	(2.2%)	17	(2.8%)
8.Spouse's sibling(s)	25	(0.3%)	2	(0.3%)
9.Child(ren)	3,390	(46.9%)	277	(46.0%)
10.Child's spouse	740	(10.2%)	23	(3.8%)
11.Grandchild(ren)	877	(12.1%)	23	(3.8%)
12.Other relatives	37	(0.5%)	4	(0.7%)
13.Other	20	(0.3%)	4	(0.7%)
No response	105	(1.5%)	33	(5.5%)

Question 13-3. The following question is directed at those who have children. Please circle the appropriate response.

Child(ren)	Medical Institutions		Patients' Groups	
	Number	(%)	Number	(%)
1.Youngest not yet school age	118	(1.6%)	20	(3.3%)
2.Youngest attends primary or junior high school	354	(4.9%)	63	(10.5%)
3.Youngest attends high school	198	(2.7%)	30	(5.0%)
4.All have finished schooling but are attending tertiary institutions	355	(4.9%)	46	(7.6%)
5.All are independent with jobs and/or have married	4,792	(66.2%)	231	(38.4%)
6.They are not yet working or married	248	(3.4%)	20	(3.3%)
7.Other	30	(0.4%)	3	(0.5%)
No response	1,140	(15.8%)	189	(31.4%)
Total	7,235	(100.0%)	602	(100.0%)

Question 14. Please tell us about your occupation.

Question 14-1. Which of the occupations in the chart below best describes your state of employment at the time you were diagnosed as suffering from cancer?

At time of diagnosis

Employment	Medical Institutions		Patients' Groups	
	Number	(%)	Number	(%)
1. Self-employed	372	(5.1%)	18	(3.0%)
2. Sole trader	345	(4.8%)	27	(4.5%)
3. Employed in family business	262	(3.6%)	35	(5.8%)
4. Executive/director	276	(3.8%)	15	(2.5%)
5. Private company employee	1,223	(16.9%)	112	(18.6%)
6. Public servant	318	(4.4%)	54	(9.0%)
7. Part-time/casual	717	(9.9%)	81	(13.5%)
8. Side-job	35	(0.5%)	5	(0.8%)
9. Full-time housewife	1,006	(13.9%)	129	(21.4%)
10.Student	13	(0.2%)	1	(0.2%)
11.Unemployed	1,140	(15.8%)	31	(5.1%)
12.Other	114	(1.6%)	26	(4.3%)
No response	1,414	(19.5%)	68	(11.3%)
Total	7,235	(100.0%)	602	(100.0%)

Current employment

Employment	Medical Institutions		Patients' Groups	
	Number	(%)	Number	(%)
1. Self-employed	272	(3.8%)	19	(3.2%)
2. Sole trader	281	(3.9%)	25	(4.2%)
3. Employed in family business	211	(2.9%)	27	(4.5%)
4. Executive/director	190	(2.6%)	12	(2.0%)
5. Private company employee	694	(9.6%)	55	(9.1%)
6. Public servant	213	(2.9%)	38	(6.3%)
7. Part-time/casual	447	(6.2%)	85	(14.1%)
8. Side-job	27	(0.4%)	2	(0.3%)
9. Full-time housewife	1,274	(17.6%)	161	(26.7%)
10.Student	3	(0.0%)	2	(0.3%)
11.Unemployed	2,079	(28.7%)	79	(13.1%)
12.Other	96	(1.3%)	26	(4.3%)
No response	1,448	(20.0%)	71	(11.8%)
Total	7,235	(100.0%)	602	(100.0%)

Question 14-2. Which of the descriptions in the chart below best describes the nature of your occupation?

At time of diagnosis

Industry	Medical Institutions		Patients' Groups	
	Number	(%)	Number	(%)
1. Agriculture, forestry, fisheries	210	(2.9%)	6	(1.0%)
2. Transport, telecommunication, security	180	(2.5%)	6	(1.0%)
3. Industrial production	555	(7.7%)	17	(2.8%)
4. Service	338	(4.7%)	23	(3.8%)
5. Retail	567	(7.8%)	43	(7.1%)
6. Clerical	567	(7.8%)	109	(18.1%)
7. Administration	452	(6.2%)	23	(3.8%)
8. Professional	389	(5.4%)	94	(15.6%)
9. Other	232	(3.2%)	42	(7.0%)
No response	3,745	(51.8%)	239	(39.7%)
Total	7,235	(100.0%)	602	(100.0%)

Currently

Industry	Medical Institutions		Patients' Groups	
	Number	(%)	Number	(%)
1. Agriculture, forestry, fisheries	165	(2.3%)	6	(1.0%)
2. Transport, telecommunication, security	112	(1.5%)	4	(0.7%)
3. Industrial production	314	(4.3%)	5	(0.8%)
4. Service	200	(2.8%)	22	(3.7%)
5. Retail	380	(5.3%)	28	(4.7%)
6. Clerical	384	(5.3%)	84	(14.0%)
7. Administration	282	(3.9%)	14	(2.3%)
8. Professional	311	(4.3%)	71	(11.8%)
9. Other	180	(2.5%)	44	(7.3%)
No response	4,907	(67.8%)	324	(53.8%)
Total	7,235	(100.0%)	602	(100.0%)

Question 14-3. Please circle the appropriate response regarding the company you were working at or the business you were running at the time of diagnosis.

Employed by someone	Medical Institutions		Patients' Groups	
	Number	(%)	Number	(%)
1. Still working	1,134	(47.5%)	115	(48.1%)
2. Retired	219	(9.2%)	10	(4.2%)
3. Resigned voluntarily	719	(30.1%)	80	(33.5%)
4. Dismissed	94	(3.9%)	17	(7.1%)
5. Other	220	(9.2%)	17	(7.1%)
Total respondents	2,386		239	

Self/family employed, sole business	Medical Institutions Number	(%)	Patients' Groups Number	(%)
1. Still operating business	638	(67.7%)	56	(71.8%)
2. Suspension of business	73	(7.7%)	6	(7.7%)
3. Not operating	53	(5.6%)	5	(6.4%)
4. Discontinued business	127	(13.5%)	8	(10.3%)
5. Under new ownership	41	(4.3%)	0	―
6. Other	11	(1.2%)	3	(3.8%)
Total respondents	943		78	

*The respondents are represented as a population parameter proportion.

Question 15. What was your after tax income during the past year? (Including pensions and allowances from family members.)

Income (yen)	Medical Institutions Number	(%)	Patients' Groups Number	(%)
1. Less than 1.2 million	423	(5.8%)	25	(4.2%)
2. 1.2 ~ 3 million	1,663	(23.0%)	80	(13.3%)
3. 3 ~ 4 million	1,228	(17.0%)	72	(12.0%)
4. 4 ~ 5 million	753	(10.4%)	47	(7.8%)
5. 5 ~ 6 million	559	(7.7%)	53	(8.8%)
6. 6 ~ 8 million	709	(9.8%)	101	(16.8%)
7. 8 ~ 10 million	499	(6.9%)	87	(14.5%)
8. 10 ~ 20 million	469	(6.5%)	80	(13.3%)
9. 20 million or more	73	(1.0%)	16	(2.7%)
No response	859	(11.9%)	41	(6.8%)
Total	7,235	(100.0%)	602	(100.0%)

Question 16A. How much did you pay to medical institutions?

Amount paid (yen)	Medical Institutions		Patients’ Groups	
	Number	(%)	Number	(%)
1. Less than 500 thousand	3,361	(46.5%)	327	(54.3%)
2. 500 thousand ~ 1 million	840	(11.6%)	52	(8.6%)
3. 1 million ~ 1.5 million	302	(4.2%)	16	(2.7%)
4. 1.5 ~ 2 million	119	(1.6%)	12	(2.0%)
5. 2 ~ 2.5 million	50	(0.7%)	2	(0.3%)
6. 2.5 ~ 3 million	34	(0.5%)	2	(0.3%)
7. 3 ~ 3.5 million	24	(0.3%)	2	(0.3%)
8. 3.5 ~ 4 million	4	(0.1%)	0	—
9. 4 ~ 4.5 million	4	(0.1%)	0	—
10. 4.5 ~ 5 million	2	(0.0%)	0	—
11. 5 ~ 5.5 million	2	(0.0%)	1	(0.2%)
12. 5.5 ~ 6 million	2	(0.0%)	0	—
13. 6 ~ 6.5 million	3	(0.0%)	1	(0.2%)
14. 6.5 ~ 7 million	1	(0.0%)	0	—
15. 7 ~ 7.5 million	2	(0.0%)	0	—
17. 8 ~ 8.5 million	2	(0.0%)	0	—
18. 8.5 ~ 9 million	1	(0.0%)	0	—
23. 11 ~ 11.5 million	1	(0.0%)	0	—
30. 14.5 ~ 15 million	1	(0.0%)	0	—
No response	2,480	(34.3%)	187	(31.1%)
Total	7,235	(100.0%)	602	(100.0%)

Question 16D. How much did you pay, other than to medical institutions, for treatment or the alleviation of after effects?

Amount paid (yen)	Medical Institutions		Patients’ Groups	
	Number	(%)	Number	(%)
1. Less than 500 thousand	1,023	(14.1%)	150	(24.9%)
2. 500 ~1 million	154	(2.1%)	23	(3.8%)
3. 1 million ~ 1.5 million	71	(1.0%)	10	(1.7%)
4. 1.5 million ~ 2 million	31	(0.4%)	3	(0.5%)
5. 2 million ~ 2.5 million	21	(0.3%)	1	(0.2%)
6. 2.5 million ~ 3 million	2	(0.0%)	1	(0.2%)
7. 3 million ~ 3.5 million	9	(0.1%)	2	(0.3%)
8. 3.5 million ~ 4 million	4	(0.1%)	0	—
9. 4 million ~ 4.5 million	0	—	2	(0.3%)
12. 5.5 million ~ 6 million	1	(0.0%)	0	—
16. 7.5 million ~ 8 million	1	(0.0%)	0	—
No response	5,918	(81.8%)	410	(68.1%)
Total	7,235	(100.0%)	602	(100.0%)

The views of 7,885 people who faced up to cancer: Towards the creation of a database of patients' anxieties

A report on research into the anxieties and burdens of cancer sufferers

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This report is a compilation of the results of the research into the anxieties and burdens of cancer sufferers, conducted by the Joint Study Group on the Sociology of Cancer, which is an amalgamation of the following three study groups:

(i) The study group for "Research into Better Medical Consultation and Psychological Care for Mainly Short-term (less than 5 years after treatment) Cancer Survivors", part of the clinical research project to establish effective medical techniques, conducted under Health and Labour Sciences Research Grants from the Ministry of Health, Labour and Welfare (MHLW),
(ii) The study group for "Research into Societal Attitudes towards Cancer Survivors", supported by a Grant-in-Aid for Cancer Research from the MHLW, and
(iii) The study group for "Research into the Improvement of Cancer Treatment in Japan", supported by a Grant-in-Aid for Cancer Research from the MHLW.