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Validation of the care notebook for measuring physical, mental and life well-being of patients with cancer

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Abstract

To measure patients' QOL in the daily practice of clinical oncology, we developed and tested the Care Notebook. This instrument has 24 questions expressed in single words or short phrases to make it more acceptable to patients. The Care Notebook, EORTC QLQ-C30 and FACIT-Sp-12 were administered to 249 outpatients with cancer. Construct validity was investigated by cluster analysis and multitrait scaling analysis. The results showed that three scales (physical well-being, mental well-being, and life well-being) could explain 55% of the variance in scores. The life well-being scale could be divided into subscales of Daily Functioning, Social Functioning, and Subjective QOL. Multitrait scaling analysis confirmed convergent and discriminant validity of these scales and subscales. Internal consistency and test-retest reliability were favorable. Differences in Care Notebook scores were also consistent with differences in performance status rating (known-groups validity), and Care Notebook scores correlated with EORTC QLQ-C30 and FACT-Sp-12 scores (concurrent validity). The Care Notebook allows clinical oncologists to easily collect valid and reliable QOL information of physical, mental, and life well-being repeatedly and with minimal burden on patients.

Key words: Care Notebook, Life well-being, Quality of life, Questionnaire, Subjective well-being

Abbreviations: CORE – Center on Outcomes, Research, and Education; ECOG – Eastern Cooperative Oncology Group; EORTC – European Organization for Research and Treatment of Cancer; EORTC QLQ-C30 – EORTC core questionnaire; FACT-G – Functional Assessment of Cancer Therapy Scale-General; FACIT-Sp-12 – Functional Assessment of Chronic Illness Therapy – The 12-item Spiritual Well-Being Scale; PSR – Performance Status Rating; QOL – Quality of Life; QOL-ACD – Quality of Life Questionnaire for Cancer Patients Treated with Anticancer Drugs

Introduction

Instruments to assess Quality of Life (QOL) in cancer patients have been developed worldwide. Such instruments include the European Organization for Research and Treatment of Cancer core questionnaire (EORTC QLQ-C30) [1], the Functional Assessment of Cancer Therapy Scale-General (FACT-G) [2], and the Quality of Life Questionnaire for Cancer Patients Treated with Anticancer Drugs (QOL-ACD) [3]. In clinical trials of anti-cancer therapy, QOL is increasingly seen as an important endpoint, and is often measured in addition to survival, tumor response, and toxicity [4].

We developed a Japanese questionnaire (the QOL-ACD); also, in cooperation with the original developers of the EORTC QLQ-C30 and the FACT-G, we developed and tested Japanese versions of those instruments. The results showed that the EORTC QLQ-C30, FACT-G, and QOL-ACD could provide valid and reliable information on Japanese patients with cancer [5–7]. However, we found that patients often have difficulty completing these questionnaires during routine clinical and palliative care. Some cancer patients were uncomfortable routinely responding to certain items (for example, items that evoked their fear of death). Completing these questionnaires also seemed to be particularly difficult for patients with poor performance status rating (PSR). In our experience [5], a total of 444 EORTC QLQ-C30 questionnaires were administered on 105 inpatients (average 4.2/patient); 370 were completed, an overall return rate of 83%. Although the return rate for PS 0–2 patients was over 99% (225/228), the corresponding rates for PS 3 and PS 4 were 81% (38/47) and 13% (9/69), respectively [5]. Furthermore, because scale scores must be computed and because the scoring must account for the polarity of the wording of each item and response choice (positive or negative), doctors and nurses found the data from these instruments difficult to use in their daily clinical practice.

Measuring QOL can have clinical benefits. QOL questionnaire uses include fostering patient-provider communication. It can help clinicians and patients to identify problems and set priorities, and to assess therapy, palliative care, and rehabilitation [8]. However, measuring QOL in clinically useful ways is not simple. To the instrument developer, the combination of clinical relevance and ease of use for both patients and clinicians is elusive. Greenfield identified two barriers to clinical use of QOL measurement: problems with the meaning and interpretation of health-status scores, and problems with utilization and mainstreaming. The latter involves all of the issues associated with changing the day-to-day behavior of clinicians and providers' routine processes to facilitate routine use of health status measures in clinical settings [9]. Similar barriers were identified by Deyo: the need to process data quickly and the need for the results to be relevant to clinical practice [10].

We therefore developed the Care Notebook, a QOL instrument that we intended to be brief, valid, reliable, easy to administer and score, and clinically useful [11].

Methods and patients

Development of the care notebook

For version 1 of the Care Notebook [12], items that seemed to influence daily life were collected from doctors, nurses, and cancer patients. The number of items was reduced according to the method of conceptual analysis [13], and also according to the frequency with which such questions were asked by doctors and nurses in clinical practice. It was found that the clinicians routinely questioned patients first about physical conditions such as pain, shortness of breath, gastrointestinal symptoms, etc., and then about mental status such as mood and depression. After that, they sometimes asked patients about relationships with family and friends, and finally about global QOL. Version 1 of the Care Notebook consisted of those items, in the order used clinically (physical well-being, mental well-being, and life well-being). Each item in version 1 was written as a complete-sentence question, with a 5-point response scale for the items of physical well-being and mental well-being, and a 10-point scale for those of life well-being.

During their encounters with patients, clinicians' questions were usually not complete sentences but only a single word or a short phrase. Therefore, version 2 of the Care Notebook included an introductory instruction followed by questions written as single words or short phrases. Items concerning spirituality were lacking in version 1, but we observed that clinicians sometimes asked these questions at the end of an interview. Items concerning spirituality were added in version 2. An 11-point scale for all the items was used for the responses. Version 2 was tested with 40 cancer patients to seek face validity, and the results were used for further refinements that led to version 3.

Structure of the care notebook (version 3)

The instrument begins with very brief instructions, which are followed by question-items in three sections: 10 items on symptoms and physical conditions (particularly those that can be affected by medical treatment), six items on moods and psychological status, and eight items related to functioning and life situations (two items each on daily physical functioning, social functioning, QOL and satisfaction, and spirituality). Each item is presented as a question consisting of one word or a short phrase. The patients respond using an 11-point scale. Finally, there is one section for unstructured responses to the question 'How might we help you improve your health and life?' (Appendix).

Sample and protocol

In this study, version 3 of the Care Notebook was tested in an outpatient clinic. The subjects were cancer patients who used the outpatient clinic of Saitama Cancer Center in March 2001. After informed consent was obtained, two sets of the Care Notebook, EORTC QLQ-C30 (1), and Functional Assessment of Chronic Illness Therapy – Spiritual well-being – The 12-item Spiritual well-being scale (FACIT-Sp-12) [14] were delivered, and answered twice at home, at an interval of 4 weeks. The patients submitted their completed questionnaires to our QOL Center without their doctor's participation. All of the procedures followed were in accordance with the Helsinki Declaration (1964, amended in 1975 and 1983) of the World Medical Association, and the protocol was approved by the Institutional Review Board of Saitama Cancer Center.

Analyses

For item convergent and discriminant validity, cluster analysis and a multi-trait scaling analysis [15, 16] were conducted. Scales and subscales were extracted by cluster analysis using the SAS program and were displayed in a dendrogram. The multi-trait scaling analysis was carried out to evaluate the extracted scale structure of the questionnaire. This technique to test discriminative validity is based on the examination of item-scale correlations. Namely, Pearson's correlations of an item with its own scale (corrected for overlap) and other scales were calculated. Item discriminant validity was supported by a comparison of the degree of correlation of an item with its own scale as compared with other scales. A scaling error was suspected when correlation of an item with another scale exceeded the correlation with its own scale [1].

The internal consistency of each scale was estimated with Cronbach's alpha [17]; a value of 0.70 or greater was considered to indicate acceptable internal consistency. Pearson's correlation coefficient was computed for test-retest reliability, and also for correlations with scores on the EORTC QLQ-C30 and FACIT-Sp-12 (concurrent validity). Student's *t*-test was used to compare the Care Notebook scores of groups with differing PSR scores (known-groups validity).

Results

Of the 266 cancer patients who used our outpatient clinic from the third to the fourth week in March 2001, 17 refused to participate in this study. Characteristics of the 249 participating patients are shown in Table 1. There were slightly more men

Table 1. Demographic and clinical characteristics (n = 249)

Variable	Category	Number	Percent	Missing
Sex	Male/female	139 / 101	(58 / 42)	9
Age	≤ 49 / 50–59 / 60–69 / ≥70	47 / 76 / 76 / 41	(20 / 32 / 32 / 17)	9
ECOG PS	0 / 1 / 2 / 3 or 4	177 / 55 / 11 / 5	(71 / 22 / 4 / 2)	9
Diagnosis	Breast cancer	70	(31)	25
	Lung cancer	50	(22)	
	Gastrointestinal cancer	40	(18)	
	Pharyngeal cancer	16	(7)	
	Lymphoma	14	(6)	
	Hepatoma	13	(6)	
	Others	17	(8)	
Stage	I / II / III / IV	20 / 49 / 56 / 56	(11 / 27 / 31 / 31)	68
Cancer disclosure	Yes/no	238 / 8	(97 /3)	3

than women. Most had progressive disease (stage III, 56 patients; stage IV, 56 patients), but had good PSR (PSR 0 or 1, 232 patients; PS 2–4, 16 patients). Almost all of the patients knew their diagnosis.

The dendrogram shows that three scales (which we call physical well-being, mental well-being, and life well-being) can explain slightly more than 50% of the total variance (Figure 1). At 75% of the total variance, life well-being was divided into three subscales (Daily Functioning, Social Functioning, and Subjective QOL). The Subjective-QOL subscale comprised four items (concerning global QOL, satisfaction, happiness, and spirituality).

With the scales described above, the multi-trait scaling analysis showed that all correlations of items with their own scale were above 0.40, indicating satisfactory item-convergent validity [1]. In the test of item-discriminant validity, one scaling error on the Appetite-Loss subscale was noted, and two scaling errors were found in the Social Functioning subscale. The rate of scaling error was 2.4% (3/126).

For test-retest reliability, Pearson's correlation coefficients for all the subscales and for the single-item symptoms were above 0.4. Cronbach's alpha coefficients for physical well-being, mental well-being, and life well-being were 0.86, 0.93, and 0.91, respectively (Table 2), indicating satisfactory internal consistency. Cronbach's alpha coefficients for all the subscales (appetite loss, constipation, fatigue, daily functioning, social functioning, and subjective QOL) showed satisfactory internal consistency (0.73 and higher).

Of the six (sub)scales tested, scores on five differed significantly between patients with a PSR of

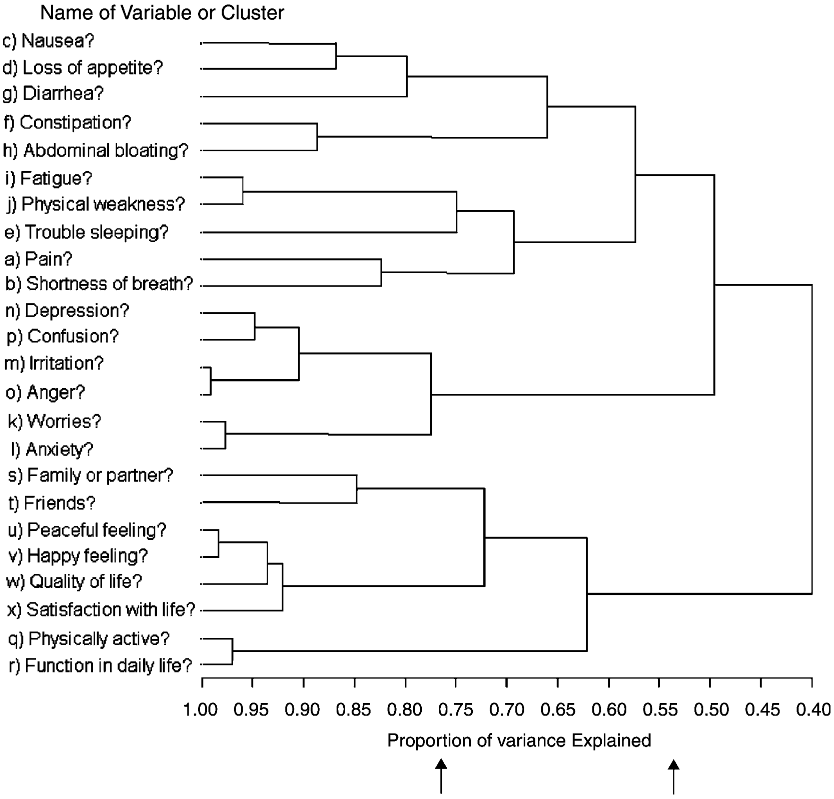

Figure 1. The dendrogram by cluster analysis shows that nine subscales can explain 75% of the total variance. The subscales can be named pain and shortness of breath, appetite loss, trouble sleeping, constipation, fatigue, mental well-being, daily functioning, social functioning, and subjective QOL. Slightly more than 50% of the total variance can be explained by three scales (interpreted as physical well-being, mental well-being, and life well-being). Therefore, life well-being scale is considered to have three subscales: daily functioning, social functioning, and subjective QOL.

Table 2. Reliability

Scale Subscale	Item	Cronbach's alpha	Test–retest reliability	Mean (SD)[a]
Physical well-being	(n = 10)	0.86		
Pain	A	–	0.66	1.63(2.39)
Shortness of breath	B	–	0.66	1.90(2.61)
Appetite loss	C, D, G	0.74	0.46	1.21(2.15)
Trouble sleeping	E	–	0.65	1.76(2.59)
Constipation	F, H	0.77	0.50	1.47(2.35)
Fatigue	I, J	0.88	0.65	2.59(2.73)
Mental well-being	K–P (n = 6)	0.93	0.68	2.31(2.54)
Life well-being	(n = 8)	0.91		
Daily functioning	Q, R	0.92	0.61	6.28(2.56)
Social functioning	S, T	0.73	0.40	8.07(2.36)
Subjective QOL	U–X	0.91	0.57	7.05(2.38)

[a] Lower scores represent lesser problems in physical and mental well-being. In life well–being, higher scores represent better QOL.

Table 3. Clinical validity: Known-groups comparison with PSR

Scale Subscale	PSR 0 Score (SE)	PSR 1- Score (SE)	*t*-test *P* value
Physical well-being	1.58 (0.13)	2.70 (0.29)	< 0.0001
Mental well-being	2.14 (0.18)	3.05 (0.31)	0.0089
Life well-being	7.36 (0.14)	6.53 (0.24)	0.0027
Daily functioning	6.69 (0.18)	5.27 (0.32)	< 0.0001
Social functioning	8.20 (0.16)	7.72 (0.31)	0.13
Subjective QOL	7.33 (0.16)	6.49 (0.26)	0.007

0 and those with a PSR greater than 0 (known-groups validity, Table 3). As expected, changes in PSR were not associated with Social Functioning. Scores on the Care Notebook scales and subscales correlated modestly or well with those on the EORTC QLQ-C30 and the FACIT-Sp-12; the only exceptions were low correlations of the Social Functioning subscale and of the item regarding diarrhea (concurrent validity, Table 4).

Discussion

Maintaining or improving patients' QOL is increasingly seen as important [8]. However, investigating patients' QOL in a busy clinical practice is difficult because the necessary steps require time, thought, recording, and follow-up [18]. The main barriers to collecting QOL data are logistic and the challenge remains to develop a method of collecting and analyzing QOL information in a manner which enhances decision making [19]. Detmar used the EORTC QLQ-C30 in clinical practice. The responses were scored by computer and displayed graphically, and both physicians and patients could see the results before the consultation. This helped them discuss HRQL issues and raised the physicians' awareness of their patients' HRQL [20]. Having similar goals with respect to clinical decision-making, and having experiences with the logistics of collecting QOL data, we developed the Care Notebook, which needs no specialized automated system using computer.

In developing version 1, we expected to measure five domains: global QOL, and physical, mental, functional, and social well-being. But the result of factor analysis with varimax rotation showed only three factors: physical well-being, mental well-being, and one factor combining functional well-being, social well-being, and global QOL [12]. In interpreting this result, we suspected that the patients assigned different weights to the five domains. Specifically, we hypothesized that these patients considered a larger domain, which we called "life well-being," to be as

Table 4. Concurrent validity with the EORTC QLQ-C30 and the FACT-Sp

Care Notebook Scale, Subscale	QLQ-C30 Scale/Item*	EORTC QLQ-C30**	FACIT -Sp-12**
Physical well-being			
Pain	Pain	**0.62**	
Shortness of breath	Dyspnea	**0.63**	
Appetite loss	Appetite loss	**0.49**	
	Nausea/vomiting	**0.46**	
	Diarrhea	0.36	
Trouble sleeping	Sleep disturbance	**0.47**	
Constipation	Constipation	**0.58**	
Fatigue	Fatigue	**0.57**	
Mental well-being	EF	**0.71**	**0.58**
Life well-being	QL	**0.55**	**0.55**
Daily functioning	PF	**0.51**	**0.46**
	RF	**0.54**	
Social functioning	SF	0.22	0.34
Subjective QOL	QL	**0.47**	**0.58**

* EF–Emotional functioning; QL–Global quality of life; PF–Physical functioning; RF–Role functioning; SF–Social functioning.

** The values of Pearson's correlation coefficients more than 0.40 are bold.

important as physical well-being and mental well-being, and that this larger domain comprised functional well-being, social well-being, and global QOL.

Therefore, we used cluster analysis in this study for version 3. This analysis resembles exploratory factor analyses in which the number of factors can be changed. As expected, slightly more than 50% of the variance could be explained by three scales: physical well-being, mental well-being, and life well-being. Increases in the percentage of the variance explained accompany increases in the number of factors (scales). In this case, at 75% of the variance explained, the Life Well-Being scale divided into subscales, which we call daily functioning, social well-being, and subjective QOL. In addition to this forward-looking cluster analysis, we used multitrait scaling analysis as a backward-looking proof. The multitrait analysis confirmed convergent and discriminant validity of these scales and subscales. The scales and subscales were also internally consistent.

Because items in the Subjective QOL subscale ask about "satisfaction with life", "quality of life", "peaceful feeling", and "happy feeling", that subscale may be similar to "subjective well-being" as described by Diener et al. [21]. Life well-being is somewhat broader. It also includes social functioning and daily functioning. The dendrogram suggests that outpatients with cancer can distinguish life well-being from their physical and psychological signs and symptoms (Figure 1). Further studies of this concept should contribute to a deeper understanding of QOL in patients with cancer.

In the validation study, test-retest reliability was not high. Correlation coefficients were above only 0.4. This was assessed over a 4-week interval, so differences in test and retest scores may have been related to important changes in disease status and HRQL. After this study, we clinically used the Care Notebook with inpatients at the Saitama Cancer Center who had lung cancer ($n = 93$; 79 men and 14 women). They answered the Care Notebook questions every Monday morning (median number of Mondays, 3; range, 1–16). Of the 93 patients, 68 had no change in PSR, so we used data from those 68 to calculate test-retest reliability over a 1-week interval. With only one exception, all the correlation coefficients were above 0.7 (pain: 0.80, shortness of breath: 0.94, appetite loss: 0.87, trouble sleeping: 0.77, constipation: 0.67, fatigue: 0.93, mental well-being: 0.92, daily functioning: 0.81, social functioning: 0.95, subjective QOL: 0.88).

Concurrent validity of the Care Notebook, the EORTC QLQ-C30, and the FACIT-Sp-12 indicate that these instruments can measure some of the same domains, even though they were developed by different methods. The only apparent problem in concurrent validity was with the social-functioning subscale: the correlation between the measured values was low (0.22) (Table 4). Both the Care Notebook and the EORTC QLQ-C30 measure 'social-functioning', but the items are quite different. The Care Notebook asks in general about relationships with 'friends' and with 'family or partner'; it does not specifically mention any possible effects of illness or of therapy. In contrast, the EORTC QLQ-C30 asks specifically about illness-related interference with "social activities" and with "family life". That difference in content may account for the low correlation. In this case, the scales have the same names despite important differences in their underlying concepts.

The Care Notebook fills a need in the daily practice of clinical oncology. By including items frequently asked by clinicians, and by writing them as single words or short phrases, we sought to obtain, in an easily repeated way, information about QOL that oncology clinicians seek in their regular interactions with patients. To elicit expressions of any concerns that are not directly addressed in the list of question-items, we included an open-ended question. We also designed the physical layout of the instrument so that it is easy to handle, and so that one volume can contain many response sheets, each of which can be separated from the others and stored in the patient's records [22].

Of the 93 inpatients mentioned above, data were obtained from 34 such patients whose PSR became 3 or 4 during their hospitalization, which indicates that the questionnaire could be used by patients with a poor performance status. Each Monday afternoon, the doctors and nurses discussed the information in each patient's Care Notebook. The unipolarity in location of the response choices facilitated these discussions (Appendix). Because problems are always indicated by circles toward the left side of the page, with just a quick glance at the response form the doctors and nurses could decide whether or not to investigate the patient's situation further. The Care Notebook also includes an open-ended question. We found that patients sometimes responded to this question, and their responses were generally of four types: conditions and mental problems to be resolved, help for improvement in daily life, questions regarding the disease (diagnosis, treatments, prognosis), and private messages from patients to clinicians. The last category includes patients' last wills, decisions regarding the future, and messages of thanks from patients to clinicians. Information discussed using Care Notebook was immediately employed in clinical practice. For examples, the doctors and nurses could make decisions with regard to treatments for pain and depression. Such decisions could be made and implemented relatively quickly.

As indicated by the previous studies using the EORTC QLQ-C30 [20, 23, 24], incorporating HRQL assessments in daily clinical oncology practice is clearly important, but the burdens these assessments impose on patients and clinicians should be minimized. The Care Notebook's brevity, validity, and reliability, together with its ease of administration, and interpretation might make it useful in clinical oncology. Its "low-tech" simplicity could also prove to be important in settings with limited financial resources. Further research testing its usefulness in routine clinical practice will be needed.

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Appendix A: Care Notebook (version 3)

As the response choices for the items are the unipolarity *in location*, answering page, i.e. the right page of the Care Notebook, presents patient' information like a graphic showing by itself. When scoring, the Care Notebook is designed to be calculated on an item-by-item basis, a subscale-score basis and a scale-score basis. Single items of pain, shortness of breath and trouble sleeping are items a, b and e, respectively. The three scales are physical well-being (items a–j), mental well-being (items k–p) and life well-being (items q–x), and the multi-item subscales are appetite loss (items c, d, and g), constipation (items f and h), fatigue (items i and j), daily functioning (items q and r), social functioning (items s and t), subjective QOL (items u–x). The score of a subscale or a scale is calculated by the sum of the item-scores per the number of the items. Lower scores represent lesser problems in physical and mental well-being. In life well-being, higher scores represent better QOL.

Although intellectual property is protected, readers can freely use and modify this instrument without permission for clinical purposes. For research, if readers describe using the Care Notebook or its constructs in their presentation or in the text of their article, then they can use and modify this instrument without permission. This instrument and further information can be obtained from < homepage3.nifty.com/care-notebook/ >.

Appendix B

Thinking about the past week, please answer the questions below by circling one number in each row on the right-hand page.

I. Did you have any of these problems?

Please circle the number that best applies to you, using 10 for the worst condition.

a) Pain?
b) Shortness of breath?
c) Nausea?
d) Loss of appetite?
e) Trouble sleeping?
f) Constipation?
g) Diarrhea?
h) Abdominal bloating?
i) Fatigue?
j) Physical weakness?

II. Did you have any of these problems with feelings or moods?

Please circle the number that best applies to you, using 10 for the worst condition.

k) Worries?
l) Anxiety?
m) Irritation?
n) Depression?
o) Anger?
p) Confusion?

III. How was your life over the past week?

Please circle the number that best applies to you, using 10 for the BEST condition.

q) Ability to be physically active?
r) Ability to function in daily life?
s) Relationship with your family or partner?
t) Relationship with your friends?
u) Peaceful feeling?
v) Happy feeling?
w) Quality of life?
x) Satisfaction with life (considering your condition and treatment)?

IV. Please tell us how we might help you improve your health and life.

Care Notebook (English version 3.1)

Month Day Year Name

I. Symptoms

a)	severe pain	10 9 8 7 6 5 4 3 2 1 0	none at all
b)	severe shortness of breath	10 9 8 7 6 5 4 3 2 1 0	none at all
c)	severe nausea	10 9 8 7 6 5 4 3 2 1 0	none at all
d)	complete loss of appetite	10 9 8 7 6 5 4 3 2 1 0	good appetite
e)	severe trouble sleeping	10 9 8 7 6 5 4 3 2 1 0	none at all
f)	severe constipation	10 9 8 7 6 5 4 3 2 1 0	none at all
g)	severe diarrhea	10 9 8 7 6 5 4 3 2 1 0	none at all
h)	severe abdominal bloating	10 9 8 7 6 5 4 3 2 1 0	none at all
i)	severe fatigue	10 9 8 7 6 5 4 3 2 1 0	none at all
j)	severe weakness	10 9 8 7 6 5 4 3 2 1 0	none at all

II. Problems with feelings or moods

k)	many worries	10 9 8 7 6 5 4 3 2 1 0	none at all
l)	severe anxiety	10 9 8 7 6 5 4 3 2 1 0	none at all
m)	severe irritation	10 9 8 7 6 5 4 3 2 1 0	none at all
n)	severe depression	10 9 8 7 6 5 4 3 2 1 0	none at all
o)	intense anger	10 9 8 7 6 5 4 3 2 1 0	none at all
p)	severe confusion	10 9 8 7 6 5 4 3 2 1 0	none at all

III. Your life over the past week

q)	unable	0 1 2 3 4 5 6 7 8 9 10	very able to be physically active
r)	unable	0 1 2 3 4 5 6 7 8 9 10	very able to function in daily life
s)	the worst	0 1 2 3 4 5 6 7 8 9 10	the best relationship with my family/partner
t)	the worst	0 1 2 3 4 5 6 7 8 9 10	the best relationship with my friends
u)	none at all	0 1 2 3 4 5 6 7 8 9 10	the most peaceful feeling
v)	none at all	0 1 2 3 4 5 6 7 8 9 10	the happiest feeling
w)	the worst	0 1 2 3 4 5 6 7 8 9 10	the best quality of life
x)	none at all	0 1 2 3 4 5 6 7 8 9 10	the most satisfaction with life

IV. How might we help you improve your health and life?

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