Koinuma N, Ito M, Ogata T	The estimated national cost of cancer in Japan	Proceedings, 66th Annual Meeting of the Japanese Cancer Association		270-271	2007
濃沼信夫、伊藤道哉、尾形倫明、三澤仁平、広中秀一、岡本直幸	実態調査にみるがん化学療法における患者自己負担の課題	日本癌治療学会	42(2)	270	2007
濃沼信夫	安心と安全の地域医療を担保する医療制度の再構築	公衆衛生	71(11)	908-913	2007
Koinuma N, Ito M, Monma Y	Place of death of cancer patients and access to home care services, Patient survey using FACIT-Sp and telephone interviewing to the physician	Quality of Life Research Supplement		A80-81	2007
濃沼信夫、伊藤道哉、門馬靖武	大腸がん術後フォローアップの経済効果に関する研究	病院管理	44 suppl	107	2007
Ogawa M, Yanoma S, Nagashima Y, Okamoto N, Ishikawa H, et al	Pradoxical discrepancy between the serum level and the placental intensity of PP5/TFPI-2 in preeclampsia and/or intrauterine growth restriction: possible interaction and correlation with gylpican-3 hold the key	PLACENTA	28	224-232	2007

Hirabayashi Y, Miyashita M, Kawa M, Kazuma K, Yamashita K, Okamoto N	Factors relating to terminally ill patients' willingness to continue living at home during the early care after discharge from clinical cancer centers in Japan	Palliative & Supportive Care	5	19-30	2007
大重賢治、岡本直幸、水嶋春朔	米国における保険者のがん検診サービスの枠組みに関する調査	公衆衛生	71(2)	102-107	2007
川上ちひろ、岡本直幸、大重賢治、杤久保　修	がん検診受診行動に関する市民意識調査	厚生の指標	54(5)	16-23	2007
Shiroiwa T, Fukuda T, Shimozuma K, Ohashi Y, Tsutani K	The model-based cost-effectiveness analysis of 1-year adjuvant trastuzumab treatment: based on 2-year follow-up HERA trial data	Breast Cancer Res Treat	online		2007
Hongo M, Kinoshita Y, Shimozuma K, Kumagai Y, Sawada M, Nii M	Psychometric validation of the Japanese translation of the Quality of Life Reflux and Dyspepsia questionnaire in patients with heartburn	J Gastroenterol	42(10)	807-815	2007
Kurita M, Shimozuma K, Morita S, Fujiki Y, Ishizawa K, et al	Clinical validity of the Japanese version of the Functional Assessment of Cancer Therapy-Anemia scale	Support Care Cancer	15(1)	1-6	2007

Shimozuma K, Imai H, Kuroi K, et al	Recent topics of health outcomes research in oncology	Breast Cancer	14(1)	60-65	2007
Ohsumi S, Shimozuma K, Kuroi K, Ono M, Imai H	Quality of life of breast cancer patients and types of surgery for breast cancer - Current status and unresolved issues	Breast Cancer	14(1)	66-73	2007
Imai H, Kuroi K, Ohsumi S, Ono M, Shimozuma K	Economic evaluation of the prevention and treatment of breast cancer - present status and open issues	Breast Cancer	14(1)	81-87	2007
Ono M, Imai H, Kuroi K, Ohsumi S, Shimozuma K	Quality of Japanese health care evaluated as hospital functions	Breast Cancer	14(1)	88-91	2007
姜哲浩、湯沢美都子、栃木香寿美、山口拓洋、下妻晃二郎、他	加齢黄斑変性患者に対する光線力学療法1年後のquality of life評価	日眼会誌	111(4)	315-321	2007
下妻晃二郎	がん告知－患者さんとのコミュニケーションスキルを上げる20か条－外来診療でできる患者満足度を向上させる工夫とは？	第7回 Junior 11	467	29-32	2007
下妻晃二郎	がん告知－患者さんとのコミュニケーションスキルを上げる20か条－教育や心理社会的介入はがん患者のQOLを向上できるか?	第6回 Junior 10	466	35-38	2007

下妻晃二郎	がん告知－患者さんとのコミュニケーションスキルを上げる 20 か条－がん患者の QOL や主観的症状を的確に把握するには？	第 5 回 Junior 10	465	31-34	2007
下妻晃二郎	看護に活かす QOL の視点－疾患別 QOL 向上に向けた実践－乳がんと QOL	臨床看護	33(12)	1742-1746	2007
下妻晃二郎、斎藤信也	緩在宅緩和医療のパス－緩和ケアにおけるクリニカルパス	緩和医療学	9(2)	131-137	2007
下妻晃二郎	がん緩和医療における QOL 評価	日本臨床	65(1)	157-163	2007
Yamazaki K, Boku N, Shibamoto K, Yasui H, Fukutomi A, Yoshino T, Hironaka S, Onozawa Y, et al	The role of the outpatient clinic in chemotherapy for patients with unresectable or recurrent gastric cancer	Jpn J Clin Oncol	37	96-101	2007
Yoshino T, Boku N, Onozawa Y, Hironaka S, Fukutomi A, Yamaguchi Y, et al	Efficacy and Safety of an Irinotecan plus Bolus 5-Fluorouracil and L-Leucovorin Regimen for Metastatic Colorectal Cancer in Japanese Patients: Experience in a Single Institution in Japan	Jpn J Clin Oncol	37	686-91	2007
Zenda S, Hironaka S, Boku N, Yamazaki K, Yasui H, et al	Impact of Hemoglobin Level on Survival in Definitive Chemoradiotherapy for T4/M1 Lymph Node Esophageal Cancer	Dis Esophagus	In press		2008

Yamazaki K, Hironaka S, Boku N, Fukutomi A, Yoshino T, Onozawa Y, et al	A retrospective study of second-line chemotherapy for unresectable or recurrent squamous cell carcinoma of the esophagus refractory to chemotherapy with 5-fluorouracil plus platinum	Int J of Clin Oncol	In press		2008
斉藤公明、菱川良夫、他	放射線治療の高度化のための超並列シミュレーションシステム	情報処理	48(10)	1081-1088	2007
Mayahara H, Hishikawa Y, et al	Acute morbidity of proton therapy for prostate cancer: the Hyogo Ion Beam Medical Center experience	Int. J. Radiat. Oncol. Biol. Phys	69(2)	434-43	2007
金子昌弘	気管支鏡の歴史	呼吸と循環	55 (2)	137-144	2007
金子昌弘	肺がん低線量ＣＴ検診	Medical Practice	25 (1)	49-51	2008
Saeki, Mizushima, Sasaki, et al	GASDERMIN, suppressed frequently in gastric cancer, is a target of LMO1 in TGF-beta-dependent apoptotic signaling.	Oncogene	126	6488-98	2007
澤田俊夫	特集「がんの緊急病態と症状マネジメント」	看護技術	53 臨時増刊号	5	2007
澤田俊夫	リレーコラム・医療地図の描き方「新病院開院と地域がん診療連携拠点病院としての役割」	月刊・保検診療	62(5)	78-79	2007
Sameshima S, Horikoshi H, Motegi K, Tomozawa S, Hirayama I, Saito T, Sawada T	Outcome of hepatic artery infusion therapy for hepatic metastases from colorectal carcinoma after radiological placement of infusion cathters	EJSO(European Journal of Surgical Oncology	33	741-745	2007

Ⅳ. 研究成果の刊行物・別刷

Geriat. Med. 45(5)：577～581, 2007

特集 長寿の秘訣

4

健康長寿のための方策—ライフスタイルの重要性—

8）がん医療にみる健康と経済

濃沼 信夫*

KEY WORD
がん
医療経済
患者自己負担
医療費
逸失利益

POINT
- がんに対する備えは，経済面も怠りなく．
- がんに罹ると，間接費用も含めて年間90万円からの自己負担が必要となる．
- がん罹患による社会的損失は，年間約10兆円に上る．

0387-1088/07/¥500/論文/JCLS

がんへの備え

現在，がんは，年間の罹患数53万人(推計値，2006年厚労省資料)，患者数142万人(総患者数，2005年患者調査)，死亡数32.6万人(全死亡の30%，2005年人口動態統計)を数える．罹患数，死亡数とも増加傾向を辿っており，生涯リスクは男性46%，女性35%(推計値，2006年厚労省資料)とされ，がんは高齢者にとって最大級の脅威である．

本年4月に施行された「がん対策基本法」の基本理念には，がん患者が等しく適切ながん医療を受けることができるようにすることが謳われている．フランスでは，がん医療は無料で受けられる(がん患者は費用負担が100%償還される)が，わが国では，がん患者にも通常の疾病と同じ費用負担が求められる．がんに対する経済面の備えは十分であろうか．

医療財源の逼迫に伴って，患者の自己負担は増加しつつある．昨年10月からは，70歳以上高齢者(現役並み所得)の窓口負担は2割から3割に引き上げられ，高額療養費制度における自己負担限度額(月額)も72,300円から80,100円(一般所得者)に引き上げられた．来年4月には，70～74歳の高齢者の自己負担が1割から2割に引き上げられる予定である．高額な抗がん剤や医療機器の登場，長い臨床経過などでも，がん患者の経済的負担は少なくないと考えられる．

がん治療に年間93万円

がんに罹患した場合に，どれほどの自己負担金が必要となるかについては，これまで十分な情報がなかった．そこで，がん患者，がんのサバイバー，がん臨床医，がん医療を扱う民間保険会社を対象に，がん医療の自己負担に関する調査を実施した．

全国の中核的ながん診療施設35病院で治療中のがん患者4,174名(回答率52.1%，平均年齢63.2歳，年間通院回数11.8回，入院日数39.4日)の回答をみると，年間の自己負担額は，

*こいぬま のぶお：東北大学大学院医学系研究科医療管理学分野

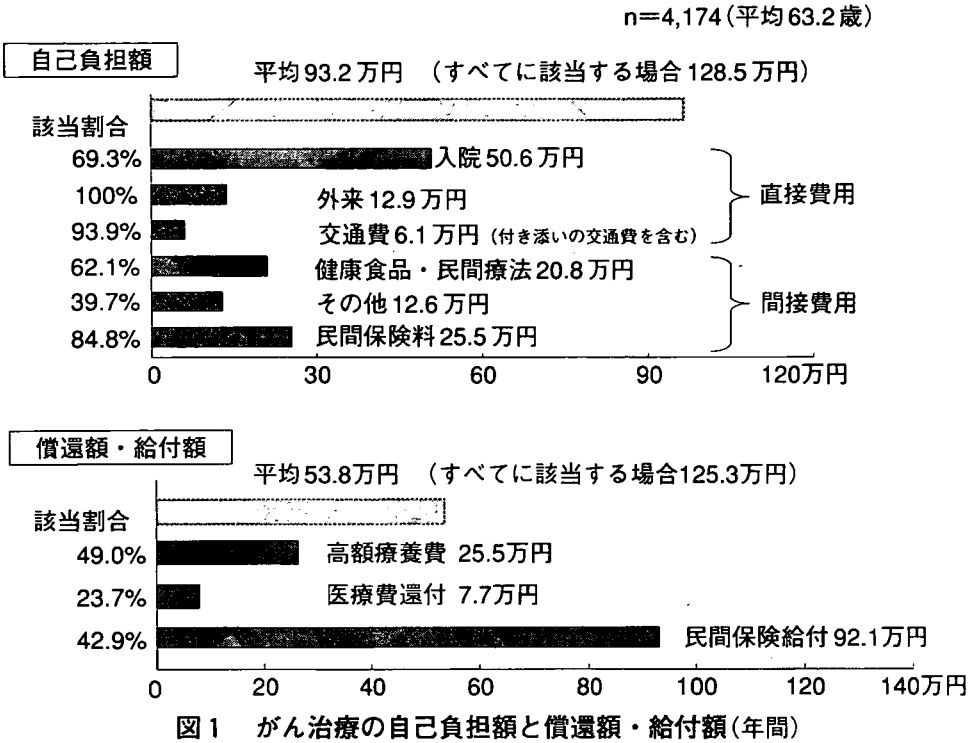

図1　がん治療の自己負担額と償還額・給付額(年間)

直接費用として，入院50.6万円，外来12.9万，交通費6.1万円である．間接費用は，健康食品・民間療法20.8万円，その他費用(贈答費，かつら代など)12.6万円，民間保険料25.5万円である．年間の自己負担額の平均は93.2万円，すべての項目に該当する場合は128.5万円である(**図1**)．

平均自己負担額を部位(27分類)別にみると，胃がん(n=505)66.4万円，大腸がん(n=267)93.7万円，肺がん(n=325)102.0万円，乳がん(n=464)77.5万円，子宮がん(n=393)90.7万円，前立腺がん(n=625)78.1万円である．

一方，高額療養費として償還を受けた患者は49.0%であり，年間償還額は25.5万円である．医療費還付を受けた患者は23.7%であり，還付額は7.7万円である．また，民間保険から給付を受けた患者は42.9%であり，給付金は92.1万円である．部位別にみると，肺がんは，高額療養費(52.4%)26.1万円，医療費還付(22.9%)8.7万円，民間保険(45.5%)105.1万円である．大腸がんは，各(52.4%)26.1万円，(22.9%)8.7万円，(45.5%)105.1万円である．

がん治療の仕事や家計への影響は少なくないこと，多くの患者で健康食品，民間療法，民間保険料など間接費用の負担が，直接費用に匹敵する水準であること，がん罹患による患者の半数が高額療養費の対象となっていることが明らかになった．がん患者は身体的，精神的負担に加え，経済的負担も大きいことが，実態調査からも伺える．

がん治療の高額負担

化学療法の分野では，高額な抗がん剤の登場で自己負担がさらに重くなっている可能性がある．化学療法を受ける患者(n=256)の年間自己負担額は平均103.3万円であり，支払いには大半が貯蓄の取り崩しや民間保険の給付金を充てられている．医療技術の進歩やDPCの普及などにより，外来での化学療法が増加しつつあるが，民間保険は主に入院を主な給付対象としているため，民間保険があてにできない場合も少なくない．経済的理由により治療に影響した患者は6.7%であり，治療を変更または中止している．

造血器腫瘍(n=60，平均年齢55.8歳)の自己

負担額は167.8万円であり，仕事への影響，収入の減少など現役世代としての悩みも少なくないことが伺える．また，粒子線治療を受ける患者(n＝143)は，先進医療としての288.3万円に加え，入院や外来の窓口負担が必要となり，年間自己負担額は470.6万円に上る．経済的理由により治療へ影響したのは9.0%であり，治療を中止・断念または延期している．

経済的理由による治療変更

がん臨床医(n＝691，回答率32.5%)に対する調査結果をみると，担当する入院患者数は平均11.1名であり，そのうち経済的な相談をした患者は1.8名である．相談内容は，高度先進医療1.0名，選定療養1.7名，分子標的治療1.0名，その他の高額な診療1.8名，その他の経済的問題1.5名である．また，担当した1日の外来患者数は25.6人であり，そのうち経済的な相談をした患者数は1.9人である．相談内容は，高度先進医療，分子標的治療，その他の高額な診療，その他の経済的問題などが多い．

6カ月間のがん診療で，経済的理由によって治療を変更した経験を有する医師は81名(11.8%)で，その患者数は106名(男性74%：女性36%，平均年齢61.0歳)である．事前に説明した医療費は平均73.8万円，治療期間は27.3日であり，変更後は各15.4万円，26.0日である．

経済的理由によって治療を変更する患者の割合を推計すると，入院で0.83%，外来で0.05%である．がん対策基本法に掲げられた患者の意向の尊重，患者中心の医療を実現する上で，患者の経済的な負担を最小化することは焦眉の急となっていることがわかる．

サバイバーの長期負担

医療技術の長足の進歩により，がんに罹患しても早期診断・治療により半数近くの患者は長期生存が期待できるようになっている．がんの5年相対生存率は男45.1%，女54.8%(1993～96年のがん患者，国立がんセンターがん対策情報センターHP)とされる．経過観察を含め，積極的ながん治療を終了したサバイバーの長期にわたる経済的負担は，がん患者と同様に大きな課題となりつつある．

治療を終えた者(n＝871，回答率47.7%，乳がんが75.0%，診断は回答時の11.2年前，治療終了は7.8年前)の年間自己負担額は，平均14.2万円である．回答者の54.0%がフォローアップなどの自己負担(窓口負担)が生じている．間接費用では，健康食品・サプリメントや保険対象外の漢方，温泉療法などの民間療法にかける費用が大きな割合を占めており，将来長期にわたり負担が継続する可能性もある．

経済的な負担に関する情報は，病院以外では，書籍(42.4%)，友人・知人(25.5%)，患者会(19.8%)，新聞(18.7%)などから得ている．インターネットは7.4%と10%以下であり，がん対策情報センターなどでの経済面を含めた情報提供の必要性がうかがえる．

民間保険の役割

がん医療を扱うすべての民間保険会社を対象に調査(n＝20，回答率41.7%)したところ，がんの年間保険料は1人平均5.5万円である．年齢別では，30歳時4.0万円，40歳時5.2万円，50歳時7.1万円，60歳時10.1万円，70歳時12.6万円と，年齢につれて高額となる．性別では，すべての年齢階級において男性の保険料が高い．がん患者に対する調査を考え合わせると，複数のがん保険に加入している者が少なくないことがうかがえる．

年間の給付額は，平均145.9万円であり，男性では45歳(5歳階級の設問)，女性では35歳，部位では造血腫瘍で最も多い給付額となっている．入院給付は回答した保険会社すべてがありとしており，手術は94.1%，診断は88.2%，通院は82.4%，死亡は70.6%である．年間給付額の平均は，死亡給付が660万円と最も高く，次いで，入院56.6万円，手術35.4万円，診断給付135.9万円，通院給付6.5万円などの順である．

表1　がんによる年間の逸失利益(主要部位別・全体)

	入院治療		外来診療		早期死亡		総計	
	金額(億円)	割合(%)	金額	割合	金額	割合	金額	割合
肺	612	14.4	123	9.5	12,238	18.0	12,973	17.7
胃	558	13.1	177	13.6	10,300	15.2	11,035	15.0
肝	334	7.8	74	5.7	7,644	11.3	8,052	11.0
結腸	346	8.1	129	9.9	4,976	7.3	5,451	7.4
直腸	242	5.7	59	4.5	3,237	4.8	3,538	4.8
乳房	156	3.7	155	11.9	3,018	4.4	3,329	4.5
前立腺	137	3.2	132	10.1	1,280	1.9	1,549	2.1
子宮	107	2.5	52	4.0	1,274	1.9	1,433	2.0
上記小計	2,492	58.5	901	69.3	43,967	64.8	47,360	64.5
全がん	4,262	100.00	1,301	100.00	67,868	100.00	73,431	100.00

将来の給付対象として検討されているのは，先進医療(保険会社の11.8%)，在宅療養(11.8%)，実額(5.9%)，自由診療(同)，終末期医療(同)などである．がん保険の将来予測(複数回答)では，支払い管理態勢の強化(84.2%)，終身保障の増加(73.7%)，リスク細分型保険の増加(73.7%)などが挙げられている．

民間保険が提供するがん保険は，入院治療とフォローアップの通院治療が主たる給付対象で，最近の医療技術の進歩や医療制度の変化，患者ニーズの多様化に必ずしも対応したものとはなっていない．患者負担の軽減という観点から，公的医療保険を補完する民間保険のあり方，およびがん医療の変化に見合う給付対象の見直しが求められる．

がん罹患による社会的損失

個人の立場とともに，国家の立場でも，がん罹患の経済的負担は大きくなっている．前述のがん対策基本法は，国を挙げてがんとの闘いに取り組むとの意志を明確にしたものである．少子高齢化，経済の長期低迷などから医療財源が逼迫する中で，がん医療にどの程度の資源を投入することが社会的に正当化されるのであろうか．

そこで，がん罹患による社会的損失(cost of cancer)の算定を試みた．これは，がんの医療費と，がん罹患・死亡の逸失利益の合計と考えられる．後者は，がん罹患による生産性低下と，がん死亡(早死)による生産性喪失である．

入院による逸失利益は，年間入院延べ患者数205.2万人で，男性2,881億円，女性1,381億円，全体4,262億円と推計される．外来受診による逸失利益は，年間患者数1,872万人で，男性785億円，女性516億円，全体1,301億円である．また，がん死亡による逸失利益は，年間がん死亡数320,358人で，男性4兆7,041億円，女性2兆827億円，全体6兆7,868億円である(**表1**)．

これから，わが国のがん罹患による社会的損失は，①がん医療費2兆3,306億円，②入院・外来受診による逸失利益5,563億円，③死亡による逸失利益6兆7,868億円の合計9兆6,737億円と推計される．

米国(NIH：Factbook-FY2004)では，新生物の年間医療費(direct medical care costs)は740億ドル(円換算8兆8,060億円)，罹患による逸失利益(morbidity costs)は175億ドル(2兆825億円)，死亡による逸失利益(mortality costs)は

1,184億ドル(14兆896億円)，合計すると2,099億ドル(24兆9,781億円)である．日米の人口や医療制度の違いを考慮すると，上記のわが国の推計値はほぼ妥当な数値と思われる．

健康長寿の経済的な価値

医療経済の観点から推計すると，がん罹患による社会的損失は年間10兆円の規模に上り，わが国のがん対策は，医療政策ばかりでなく経済政策としても極めて重要と考えられる．がん罹患による社会的損失を減少させるためには，有効ながん対策であれば，巨額の資源投入を行うことも社会経済的に許容され得ることが示唆される．これを個人にブレイクダウンすれば，がんに罹らなかった(健康長寿)の経済的価値とみることができる．

(本稿は，厚生労働科学研究費補助金第3次対がん総合戦略研究事業「がんの医療経済と患者負担に関する研究」(2004～2006年度)，および，厚生労働省がん研究助成金「本邦におけるがん医療の適正化に関する研究：がん医療資源の有効活用に関する研究」(同)の結果の一部である．)

(執筆者連絡先)　濃沼信夫　〒980-8574　宮城県仙台市青葉区星陵町2-1　東北大学大学院医学系研究科医療管理学分野

Palliative and Supportive Care (2007), 5, 19–30. Printed in the USA.

DOI: 10.1017/S1478951507070046

Factors relating to terminally ill cancer patients' willingness to continue living at home during the early phase of home care after discharge from clinical cancer centers in Japan

YUKA HIRABAYASHI, R.N., PH.D.,[1] MITSUNORI MIYASHITA, R.N., PH.D.,[2] MASAKO KAWA, R.N., PH.D.,[2] KEIKO KAZUMA, R.N., PH.D.,[2] KOHSUKE YAMASHITA, M.D.,[3] AND NAOYUKI OKAMOTO, PH.D.[4]

[1]Statistics and Cancer Control Division, Research Center for Cancer Prevention and Screening, National Cancer Center, Tokyo, Japan
[2]Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, The University of Tokyo, Tokyo, Japan
[3]Department of Radiotherapy, Kanagawa Cancer Center, Yokohama, Japan
[4]Department of Epidemiology, Research Institute, Kanagawa Cancer Center, Yokohama, Japan

(RECEIVED July 30, 2006; ACCEPTED August 27, 2006)

ABSTRACT

Objective: To assess the willingness of Japanese terminally ill cancer patients to continue living at home during the early phase of home care after discharge from a Clinical Cancer Center (CCC) in Japan, and to identify factors relating to their willingness to continue living at home.

Methods: A cross-sectional questionnaire survey of a convenient sample of both Japanese terminally ill cancer patients and their caregivers (PFCs) was conducted (n = 294, effective response rate 25.0%). Questionnaires were mailed and medical records were accessed for 73 pairs of respondents, comprising one terminally ill cancer patient and one PFC.

Results: At about 10 days after discharge, 64 patients (88%) wished to continue living at home. A hierarchical logistic regression analysis was performed on the data. It was found that the fewer the medical treatments undergone (OR = 0.20, 95% CI: 0.05–0.72), the higher the patients' perception that their condition was consistent with care at home (OR = 2.77, 95% CI: 1.08–8.62) and with their functional well-being (OR = 1.45, 95% CI: 1.08–2.17). In addition, the higher the caregivers' satisfaction with life (OR = 2.37, 95% CI: 1.15–5.77), the more willing patients tended to be to continue living at home.

Significant of results: The willingness of Japanese terminally ill cancer patients to continue living at home appears to be affected by caregiver status. This indicates a need for discharging facilities to monitor the state of home assistance and to investigate the nature of assistance required for continuing home care.

KEYWORDS: End-of-life care, Terminally ill cancer, Willingness to continue living at home, Palliative home care, Clinical Cancer Center

INTRODUCTION

In Japan, cancer is the primary cause of death (about 30%), with about 300,000 people dying from it each year (Ministry of Health, Labour and Welfare Percentage, 2006). Assurance of end-of-life cancer care in Japan was established when "palliative care unit fees" were first incorporated in the treatment fees paid to medical institutions under the medical insurance system (Umeda & Iwasaki, 2001). Guidance and management fees for cancer patients living at home and treatment fees paid to medical institutions for home terminal cancer patients were

Corresponding author: Yuka Hirabayashi, Statistics and Cancer Control Division, Research Center for Cancer Prevention and Screening, National Cancer Center, 5-1-1 Tsuikiji Chuo-ku, Tokyo 104-0045, Japan. E-mail: yuimamur@gan2.res.ncc.go.jp

also established under the medical insurance system. An "additional palliative care treatment fee," for treatment in general hospitals by palliative care teams that meet given criteria, was further established in 2002 (Komoto, 2002). As a result, appropriate, ongoing palliative care is now available at all stages of the treatment of cancer patients, and a smooth transition of patients to palliative care units and home palliative care is expected.

The period immediately after discharge, that is, the week or two preceding the first outpatient visit, is fraught with various problems associated with the transition to home care (Okaya, 2000; Sakai, 2002). Providing information about emergency measures suited to the physical state of the patient, coordinating the many home medical care and welfare-related professional services, and assisting with complicated issues that increase the anxiety of patients and primary family caregivers (PFCs) are considered to be important (Okaya, 2000; Hakata et al., 2002). Few patients make the decision to "live at home until the end" during the initial period of home care, but it is reported that many talk it over with their families and make the decision when their living situation has become clear, between the end of the initial period and 1 to 3 weeks prior to death (Okaya, 2000). Thus, the extent to which the patient wishes to live at home and whether assistance that is consistent with the patient's wishes is given are necessary considerations in the home care process. Adequate assessment and support during the initial period of home care is of prime importance.

The levels of pain experienced by terminally ill cancer patients are a source of anguish for the patient's entire family (i.e., the family caring for the patient) (Tsuneto, 1999; Suzuki et al., 2001). It is presumed that the physical and mental state of PFCs is affected by the physical and mental state of the patient (Rossi Ferrario et al., 2003), and also that the desire of PFCs to provide home care, together with their perception of burden or of well-being and satisfaction with life, will affect the quality of life of the patient and the patient's willingness to continue living at home (Sawada et al., 2001). The finding that the stronger the wish of both patient and PFCs to continue home care the more likely it is that the patient will die at home (Schaapveld & Cleton, 1989; Ishigaki, 1998) suggests that taking into account the experience of not only the patient but also the family is vital to continuing home care (Kaye, 1999).

An understanding of the factors affecting terminally ill cancer patients' willingness to continue living at home during the period of transition from Clinical Cancer Centers (CCCs) to home care will permit the development of a concrete strategy for the improvement the home care environment, and this can be expected to raise retention rates. It will thus contribute to the overall improvement of the experience of palliative care for terminally ill cancer patients and their family members.

The objectives of this study were (1) To identify the current rate of willingness of terminally ill cancer patients to continue living at home after discharge from CCCs in Japan and and (2) to identify factors associated with the willingness of the patients to continue living at home.

METHODS

Sample

The subjects were terminally ill cancer patients discharged from CCC institutions and their PFCs. All approved of the study and participated voluntarily, and written consent was obtained. The eligibility criteria were (1) terminally ill cancer patient and the patient's PFCs, (2) aged 18 years or older, (3) free from impaired consciousness and psychiatric disorders, and (4) the physician in charge approved the patient's participation.

CCCs are hospitals and equivalent medical facilities in Japan engaged in research into and prevention, diagnosis, and treatment of cancer and other malignant neoplasms and holding seminars for health care professionals.

Study Samples

A total of 294 pairs of patients and PFCs were selected from 13 of the 27 CCCs that agreed to participate in the study. Then 143 eligible patients (49%) and 121 eligible PFCs (41%) returned their completed questionnaire. Of these, 59 patients and 37 PFCs were not eligible, and 11 patients and 11 PFCs expressed a lack of desire to participate in the study by return postcard. As a result, data from 73 pairs of patients and PFC (25%) were ultimately analyzed. Table 1 shows the characteristics of the patients and PFCs.

Procedure

In September 2001, requests for participation in the study were mailed to all of the Japanese Association of Clinical Cancer Centers asking for their cooperation. The cover letter explained that the survey would be both confidential and anonymous. The CCCs were requested to supply the details of eligible patients. If the CCCs had had eligible patients during the study period, they selected all

Table 1. *Characteristics of the respondents (n = 73)*

A. Characteristics of patients	No. of patients	%	Characteristics of patients		No. of Patients	%
Sex						
Female	30	41	Performance status	0	37	51
Male	43	59		1	21	29
Age				2	10	14
Mean ± *SD*	62.2 ± 10.9			3	4	5
Range	37–84			4	1	1
Education			Total length of hospitalization (days)			
Junior high school	15	21		Mean ± SD	45.7 ± 34.9	
High school	28	38		Median	34	
Technical school/junior college	16	22		Range	3–165	
University/postgraduate	12	16	No. of medical	0	44	60
Unknown	2	3	treatments	1	17	23
Time since discharge (days)				2	8	11
Mean ± SD	9.5 ± 4.4			3	3	4
Median	11			4	1	1
Range	7–28			Mean ± *SD*	0.5 ± 0.9	
Primary site				Median	1	
Digestive system	25	34		Range	0–4	
Lung/pleura	17	23	Type of medical			
Gynecologic	6	8	(Multiple choice)	Pain management	26	36
Hematopoietic system	6	8		IVH	6	8
Mammary gland	7	10		Self-injection	4	5
Other	12	16		Colorectum stoma care	3	4
Metastasis				Indwelling catheter	2	3
Present	50	68		Self-catheterization	2	3
Absent	23	32		Bedsore treatment	1	1
Stage				Other	6	8
III	16	22	Perception of cancer	Present	68	93
IV	51	70	at discharge	Absent	4	5
Unknown	6	8		Unknown	1	1
Therapy			Desire for home care	Present	47	64
Surgery	36	49		Absent	26	46
Chemotherapy	63	86				
Radiotherapy	28	38				
Opioid	20	27				

B. Characteristics of PFCs	*N*	%	Characteristics of PFCs		*N*	%
Sex						
Female	46	63	Primary caregiver			
Male	27	37		Spouse	54	74
Age (years)				Child	11	15
<40	7	10		Parent	3	4
40–49	14	19		Sibling	3	4
50–59	22	30		Friend	1	1
60–69	20	27		Other	1	1
≥70	10	14	Secondary caregiver			
Mean ± *SD*	56.3 ± 12.7			Present	67	92
Median	55.5			Absent	6	8
Range	22–91		Desire for home care			
Education				Present	47	64
Junior high school	11	15		Absent	26	36
High school	35	48				
Technical school/junior college	13	18				
University, postgraduate	11	15				
Unknown	3	4				

eligible patients ready for discharge after the study began.

Ethical Considerations

The study was conducted only after obtaining the approval of the Institutional Review Board of Kanagawa Cancer Center and of each institution. The subjects were informed in writing in the cover letter of the role of participants and of the procedures for ensuring privacy in the handling of data and protecting patient rights. Written consent was obtained prior to the commitment to participate and again at the commencement of participation. All data in the present study were rigorously managed by the researchers so as to ensure privacy.

Questionnaire

The questionnaire was developed based on a systematic literature review (World Health Organization, 1990; Nagae, 1998; Okamoto, 1998; Miyashita et al., 1999; Naylor et al., 1999; Nagae et al., 2000; Naylor, 2000; Ogata et al., 2000) and on pilot study interviews with several terminally ill cancer patients and their PFCs, two directors of home nursing stations providing terminal cancer care, and four oncologists as well as on the experience of the investigators.

The researchers developed the framework of the study (Fig. 1). We proposed two groups of factors associated with the willingness of patients to continue living at home: patient factors and PFC factors. The former were divided into predischarge "patient characteristics," which had been defined at discharge and could not be changed (or were difficult to change) by health care and welfare professionals, and "patient discharge-related information," which was both documented and related to matters that occurred after discharge or could be altered by subsequent events. These data were normally used for postdischarge evaluation, in the wake of discharge assistance. PFC factors were related to the characteristics of PFCs.

The study variables were grouped as follows:

1. Patient sociodemographic variables (sex, age, education level).
2. Patient clinical and functional variables: diagnosis; metastasis; stage; therapy undergone before discharge (surgery, chemotherapy, radiotherapy, etc); perception of cancer at discharge; number of medical treatments; performance status (Eastern Cooperative Oncology Group Performance Status; PS) scale (European Organization for Research and Treatment of Cancer, 1996), whose scores range from 1 to 4 (higher scores represent greater functional dependence); and presence or absence of patient desire for home care at discharge.

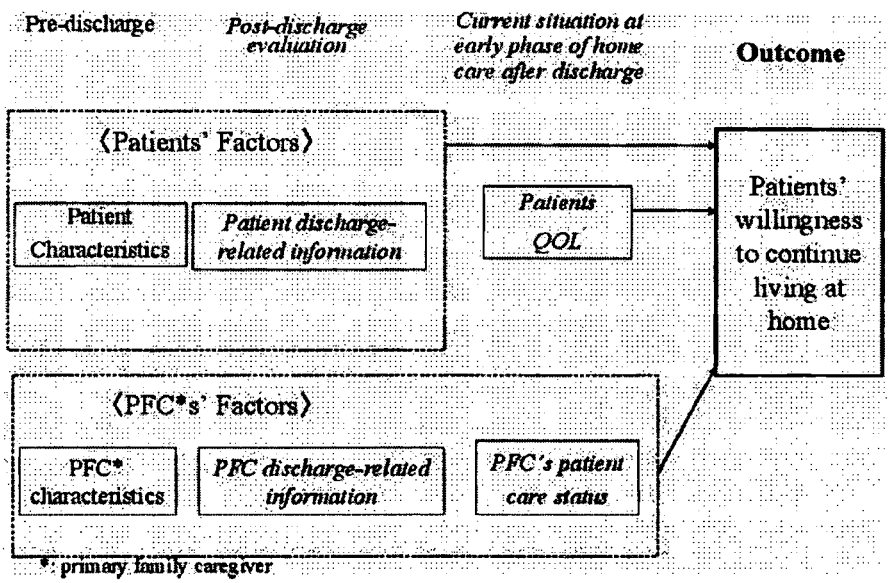

Fig. 1. Research framework of terminally ill cancer patients' and their primary family caregivers' willingness to continue living at home during the early phase of home care after discharge.

3. Patient discharge-related information: patient relationship with PFCs; extent of gap between home care envisioned at discharge and reality; patient satisfaction with discharge care (eight items; five-point scale from "very unsatisfactory" (0) to "very satisfactory" (4): The total score of eight items was used as a single subscale in the subsequent analyses, due to good internal consistency (Cronbach's alpha coefficient = .91), a higher score indicating higher satisfaction with discharge care, within a possible range of 0–32); and stability of correspondence of reality to their image of living at home before discharge.
4. Patient's quality of life: assessed using the subscales of the 27-item Japanese version of FACT-G (QOL). QOL consists of four domains: physical well-being (PWB, 7 items; range 0–28), social well-being (SWB, 8 items; range 0–32), emotional well-being (EWB, 5 items; range 0–20), and functional well-being (FWB, 7 items; range 0–28). Each response was calibrated using a five-point scale. Higher scores indicate higher levels of well-being (Cella, 1997).
5. PFC variables: sociodemographic variables (sex, age, education level); relationship with patient; extent of gap between home care as envisioned at discharge and reality; presence or absence of other family caregivers; and satisfaction with discharge care. The same items as for patients were employed (Cronbach's alpha coefficient = .89).
6. Characteristics of caregiver's support at the time the questionnaire was filled out (after discharge): eight items relating to the PFCs' perception of burden in their situation, such as arrangements for and information held relating to support available when there are changes in medical treatment, or whether respite care is utilized. Respondents chose one of five responses from "inapplicable" to "very applicable."
7. The patient's and the PFC's willingness, or not, to continue with living at home arrangements in the future.

Statistical Analysis

To determine the potential determinants of patients' willingness to continue living at home from the data, preliminary univariate analyses were conducted, as appropriate, using the unpaired t test, the chi-square test (Fisher's exact methods), and the trend test (Cochran–Armitage's trend test) for contingency tables with ordinal data.

The next objective was to simultaneously explore the relationship to patients' willingness to continue living at home to the groups of items covering "patient characteristics," "patient discharge-related information," "patient QOL," and "PFCs' status"

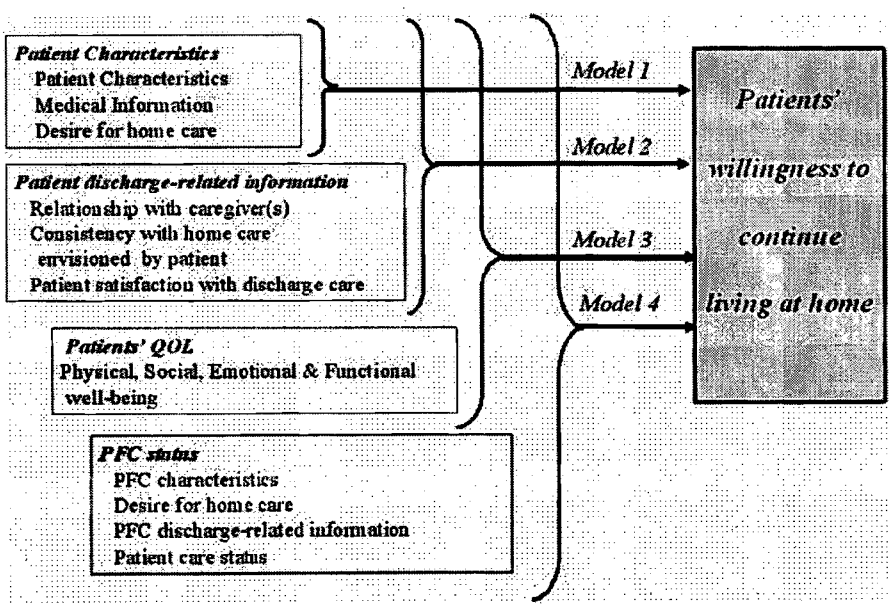

Fig. 2. Analysis model of factors related to patients' willingness to continue living at home during the early phase of home care after discharge.

(Fig. 2). After the univariate analysis, a hierarchical logistic regression analysis (backward elimination; $p > .2$), in four steps, was performed to extract the higher determinants of the patients' willingness to continue living at home: Model 1 consisted of "patient characteristics" alone; Model 2 consisted of Model 1 with "patient discharge-related information" added; Model 3 consisted of Model 2 with "patient QOL" added; and Model 4 consisted of Model 3 with "caregiver status" added. Data analyses were conducted using the SAS ver.8.2 statistical software package (SAS Institute, Cary, NC, USA). All p values were two-tailed and statistical significance was set at the $p < .05$ level.

RESULTS

Patients' Willingness to Continue Living At Home and Related Factors

At about 10 days after discharge, 64 patients (88%) wished to continue living at home. The significance levels of the correlations between patients' willingness to continue living at home and patients' and PFCs' sociodemographic variables are shown in Table 2.

The willingness to continue living at home was significantly lower in patients who underwent a larger number of medical treatments than in patients who underwent fewer treatments ($p = .05$). Patients who had desired home care at discharge also showed a significantly greater willingness to continue living at home ($p = .05$). The more consistent patients felt that their home care after discharge was as they envisioned it before discharge, the more willing they were to continue ($p = .01$). And finally, the higher the score for emotional well-being and the higher the score for functional well-being, the more willing patients were to continue living at home ($p = .01$ and $p = .03$, respectively).

Turning our attention to PFC variables, the fewer PFCs who expressed the need for further care-related support, the more patients responded that they were willing to continue living at home ($p = .002$). In addition, the higher the caregivers' satisfaction with life, the more willing patients tended to be to continue living at home ($p = .19$).

For variables that exhibited a significant correlation in the univariate analysis, a hierarchical logistic regression analysis was performed using age, sex, and four domains of QOL as independent variables (Table 3).

In Model 1, the number of medical procedures undergone (OR = 0.49, 95% CI: 0.23–0.97, $p < .05$) was significant. In Model 2, the number of medical procedures (OR = 0.44, 95% CI: 0.19–0.90, $p < .05$) and the perception of consistency between care at home as envisioned by the patient and the reality (OR = 2.70, 95% CI: 1.34–6.41, $p < .05$) were both significant. In Model 3, the number of medical procedures undergone (OR = 0.39, 95% CI: 0.13–0.94, $p < .05$) and level of functional well-being (OR = 1.36, 95% CI: 1.06–1.94, $p < .05$), as a domain of patient QOL, were significant. The perception of consistency of care at home as envisioned by the patient and the reality (OR = 2.39, 95% CI: 0.95–7.19, $p < 0.2$) was no longer statistically significant in Model 3.

In Model 4, the significance of number of medical procedures (OR = 0.20, 95% CI: 0.05–0.72, $p < .05$) was low, the significance of perception of consistency of care at home as envisioned by the patient and the reality (OR = 2.77, 95% CI: 1.08–8.62, $p < .05$) was high, the significance of functional well-being (OR = 1.45, 95% CI: 1.08–2.17, $p < .05$) was high, and the higher the caregivers' satisfaction with life (OR = 2.37, 95% CI: 1.15–5.77, $p < .05$), the more willing the patient tended to be to continue living at home.

The model contribution ratios were 17%, 30%, 39%, and 50% for Models 1, 2, 3, and 4, respectively, increasing in order from Models 1 to 4.

DISCUSSION

In the present study, we investigated factors relating to the willingness of patients, early in the period of transition from CCC to home care, to continue living at home, in order to identify possible concrete support strategies for terminally ill cancer patients in this period of home care.

The Association between Characteristics of the Early Phase of Home Care and the Willingness of Terminally Ill Cancer Patients to Continue Living at Home

This study revealed that the physical and psychological burden caused by a large number of medical treatments and inconsistency between home care as envisioned and its reality were factors that made it difficult to accept the continuance of home care (Kaye, 1999). Another important finding is that care provided after discharge should be, as far as possible, consistent with that envisioned by patient before discharge.

Discharge services should address this aspect (Naylor et al., 1999, 2000; Naylor, 2000). Furthermore, the factor where the greater the patient's perception of functional well-being, the more likely are the functions of daily living to proceed smoothly

Table 2. *Result of univariate analysis on patients' willingness to continue living at home (n = 73)*

Patient characteristics	Patients' willingness to continue living at home: Present (n = 64) No. of patients (%)	Absent (n = 9) No. of patients (%)	p value
A. Patient Characteristics			
Age (years)			
<40	1 (50)	1 (50)	0.42[1]
40–49	8 (80)	2 (20)	
50–59	25 (93)	2 (7)	
60–69	14 (88)	2 (13)	
≥70	16 (89)	2 (11)	
Sex			
Female	24 (80)	6 (20)	0.76[2]
Male	40 (93)	3 (7)	
Education			
Junior high school	15 (100)	0 (0)	0.21[2]
High school	24 (86)	4 (14)	
Technical school/junior college	12 (75)	4 (25)	
University, postgraduate	11 (92)	1 (8)	
B. Medical Information			
Primary site			
Digestive system	23 (88)	2 (12)	0.38[2]
Lung/pleura	15 (92)	2 (8)	
Gynecological	6 (100)	0 (0)	
Hematopoietic system	6 (100)	0 (0)	
Mammary gland	5 (71)	2 (29)	
Other	9 (75)	3 (25)	
Metastasis			
Present	43 (86)	7 (14)	0.74[2]
Absent	21 (91)	2 (9)	
Stage			
III	15 (94)	1 (6)	1.00[2]
IV	45 (88)	6 (12)	
Total length-of hospitalization (days)			
<30	27 (84)	5 (16)	0.62[1]
30–59	15 (88)	2 (12)	
60–89	15 (94)	1 (6)	
>≠90	7 (88)	1 (13)	
Performance status			
0	34 (92)	3 (8)	0.37[1]
1	17 (81)	4 (19)	
2	10 (100)	0 (0)	
3	2 (50)	2 (50)	
4	1 (100)	0 (0)	
Surgery			
Yes	31 (86)	5 (14)	0.74[2]
No	33 (89)	4 (11)	
Chemotherapy			
Yes	55 (87)	8 (13)	1.00[2]
No	9 (90)	1 (10)	
Radiotherapy			
Yes	25 (89)	3 (11)	1.00[2]
No	39 (87)	6 (13)	
No. of medical treatments			
0	40 (91)	4 (9)	0.05*[1]
1	16 (94)	1 (6)	
2	5 (63)	3 (38)	
3	3 (100)	0 (0)	
4	0 (0)	1 (100)	

(*continued*)

Table 2. *Continued*

Patient characteristics	Patients' willingness to continue living at home: Present (n = 64) No. of patients (%)	Absent (n = 9) No. of patients (%)	p value
C. Desire for home care			
Present	43 (91)	4 (9)	0.05*[2]
Absent	21 (81)	5 (19)	
Patient discharge-related information			
Relationship with caregiver(s)			
Not at all good	0 (0)	0 (0)	0.30[1]
Marginally good	0 (0)	0 (0)	
Somewhat good	3 (100)	0 (0)	
Quite good	9 (69)	4 (31)	
Extremely good	52 (91)	5 (9)	
Consistency with home care envisioned by patient			
Completely different	0 (0)	0 (0)	0.01**[1]
Quite different	0 (0)	1 (100)	
Somewhat different	10 (71)	4 (29)	
Marginally different	4 (100)	0 (0)	
Identical	50 (93)	4 (7)	
Patient satisfaction with discharge care (score)[3] (range 0–32)	(73)		
<21 points	11 (73)	4 (27)	0.29[1]
21–25 points	19 (91)	2 (10)	
26–27 points	11 (100)	0 (0)	
>≠28 points	23 (89)	3 (12)	
Patient QOL(FACT-G)			
Physical well-being[3] (range 0–28)			
<12 points	14 (78)	4 (22)	0.26[1]
12–19 points	20 (95)	1 (5)	
20–23 points	14 (78)	4 (22)	
>≠24 points	16 (100)	0 (0)	
Social Well-being[3] (range 0–32)			
<21 points	6 (100)	0 (0)	0.46[1]
21–23 points	2 (80)	0 (20)	
24–27 points	5 (91)	1 (9)	
>≠28 points	51 (85)	8 (15)	
Emotional well-being[3] (range 0–20)			
<10 points	13 (72)	5 (28)	0.01**[1]
10–12 points	19 (86)	3 (14)	
13–16 points	14 (93)	1 (7)	
>≠17 points	18 (100)	0 (0)	
Functional well-being[3] (range 0–28)			
<12 points	25 (78)	7 (22)	0.03*[1]
12–17 points	27 (93)	2 (7)	
18–21 points	11 (100)	0 (0)	
>≠22 points	1 (100)	0 (0)	
PFC status			
D. PFC characteristics			
Age (years)			
<40	7 (100)	0 (0)	0.30[1]
40–49	11 (79)	3 (21)	
50–59	21 (95)	1 (5)	
60–69	18 (90)	2 (10)	
>≠ 70	7 (70)	3 (30)	
Sex			
Female	39 (85)	7 (15)	0.53[2]
Male	25 (93)	2 (7)	
Education			
Junior high school	9 (82)	2 (18)	0.84[2]
High school	31 (89)	4 (11)	
Technical school/junior college	11 (85)	2 (15)	
University/postgraduate	10 (91)	1 (9)	

(continued)

Table 2. *Continued*

Patient characteristics	Patients' willingness to continue living at home: Present (n = 64) No. of patients (%)	Absent (n = 9) No. of patients (%)	p value
E. Desire for home care			
Present	42 (89)	5 (11)	0.34[2]
Absent	22 (85)	4 (15)	
F. PFC discharge-related information			
Relationship with patient			
Spouse	49 (91)	5 (9)	0.33[1]
Child	8 (73)	3 (27)	
Parent	3 (100)	0 (0)	
Sibling	2 (67)	1 (33)	
Friend	1 (100)	0 (0)	
Other	1 (100)	0 (0)	
Secondary caregiver(s)			
Present	58 (87)	9 (13)	0.49[2]
Absent	6 (100)	0 (0)	
PFC satisfaction with discharge care[3] (range 0–32)			
<21 points	11 (92)	1 (8)	0.43[1]
21–25 points	21 (91)	2 (9)	
26–27 points	10 (83)	2 (17)	
>≠28 points	22 (85)	4 (15)	
G. Patient care status			
Support and information are available when there are changes in care status			
Not true	15 (100)	0 (0)	0.28[1]
Marginally true	11 (79)	3 (21)	
Somewhat true	12 (92)	1 (8)	
Quite true	12 (86)	2 (14)	
Very true	14 (82)	3 (18)	
You feel healthy			
Not true	5 (71)	2 (29)	0.79[1]
Marginally true	11 (92)	1 8)	
Somewhat true	17 (100)	0 (0)	
Quite true	15 (88)	2 (12)	
Very true	16 (80)	4 (20)	
Respite from care			
Not true	2 (100)	0 (0)	1.00[1]
Marginally true	2 (67)	1 (33)	
Somewhat true	17 (85)	3 (15)	
Quite true	24 (96)	1 (4)	
Very true	19 (83)	4 (17)	
Additional support etc			
Not true	31 (97)	1 (3)	0.01**[1]
Marginally true	11 (85)	2 (15)	
Somewhat true	14 (93)	1 (7)	
Quite true	5 (83)	1 (17)	
Very true	3 (43)	4 (57)	
Satisfied with life (satisfied with present QOL)			
Not true	4 (100)	0 (0)	0.19††[1]
Marginally true	7 (100)	0 (0)	
Somewhat true	10 (83)	2 (17)	
Quite true	18 (95)	1 (5)	
Very true	2 (25)	6 (75)	

[1]Cochran-Armitage's trend test, [2]Fisher's exact test, [3]Percentile point
††$P < 0.2$, †$P < 0.1$,*$P < 0.05$, **$P < 0.01$