図14　連携に失敗する／はぐくむ病状説明

紹介元	治療がうまくいってますからこれからは近くの先生に診てもらいましょう． …紹介できて肩の荷が下りた 今後悪くなってゆくことは伝えていない	⇔	今後次第に悪くなると思いますが，今の治療はうまくいってます．これからしばらくは近くの先生に見てもらいましょう． 困ったことがあればいつでも相談に乗ります．
紹介先	だんだん悪くなってきて，「悪くなってきたのは治療が悪いせい」と患者にいわれる …次からひき受けるものか！	⇔	悪くなってきても「自宅近くでいい治療が長く続けられたことはよかった」と感謝される．

しっかりとした病状説明（告知）が連携の最低条件

Palliative Care Research 2011; 6(2): 237-245

短報

進行がん患者と遺族のがん治療と緩和ケアに対する要望
― 821 名の自由記述からの示唆 ―

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受付日 2011 年 7 月 21 日／改訂日 2011 年 9 月 8 日／受理日 2011 年 9 月 12 日

より良い緩和ケアを提供するために, がん患者やその家族の意見を収集することは重要である. 本研究の目的は,「緩和ケア普及のための地域プロジェクト」(OPTIM) の介入前に行われた, 進行がん患者と遺族を対象とした質問紙調査で得られた自由記述欄の内容を分析し, がん治療と緩和ケアに対する要望と良かった点を収集・分類することである. 全国 4 地域の進行がん患者 1,493 名, 遺族 1,658 名に調査票を送付し, 回収した調査票のうち, 自由記述欄に回答のあったがん患者 271 名, 遺族 550 名を対象とした. 本研究の結果から, がん患者と遺族は, 患者・医療者間のコミュニケーションの充実, 苦痛緩和の質の向上, 療養に関わる経済的負担の軽減, 緩和ケアに関する啓発活動の増加, 病院内外の連携システムの改善, などの要望を持っていることが明らかとなった.

Palliat Care Res 2011; 6(2): 237-245

Key words: 緩和ケア, 内容分析, 自由記述

緒　言

2007 年に「がん対策基本法」が施行されて以降, 緩和ケアの普及はわが国の喫緊の課題である1). しかし, わが国のがん患者のうち専門的緩和ケアを受けたことがある患者は 10% を下回り2,3), これは欧米に比して低い割合である4〜6). また, 緩和ケア病棟を利用した患者の遺族のうち, 50% がケアの改善を求めている2). これらの背景から, 量, 質ともに, わが国の緩和ケアに対する早急な対策が必要であるといえる. そのためには, 患者や家族を含めた多方面から意見を収集することが重要であるが, これまでのわが国の研究では, 多地域の複数施設の進行がん患者を連続的に対象としたものはなく, 一般病棟や在宅療養の遺族を対象としたものもほとんどない7,8).

緩和ケア普及のためのモデルづくりを目的として,「緩和ケア普及のための地域プロジェクト」(以下, OPTIM) が行われた9). 本研究はその前調査として行われた質問紙調査で得られた, 自由記述欄の回答を分析することにより, 患者と遺族の要望を分類し, 今後必要とされる改善点を明らかにすることを目的とした.

方　法

1 対　象

1. 対象地域

本調査は, OPTIM の前調査として行われたため, OPTIM の介入対象地域である鶴岡地域 (山形県鶴岡市・三川町), 柏地域 (千葉県柏市・流山市・我孫子市), 浜松地域 (静岡県浜松市), 長崎地域 (長崎県長崎市) を対象に行われた.

2. 患者調査

対象施設は, 4 地域でがん診療を行っている病院と同定された 34 病院 (11,033 床) のうち, 患者調査への参加同意が得られた 23 病院 (68% ; 8,964 床, 81%) とした.

対象者は, 2007 年 12 月〜2008 年 3 月までに対象施設で外来受診をした患者のうち, 次の適格基準を満たす者とした. ①がんに対する診療が主たる目的で当該施設の外来に受診している, ②対象地域に居住している, ③がん原発部位が肺, 胃・食道, 肝臓・胆嚢・膵臓, 結腸・直腸, 乳腺, 泌尿器, 子宮・卵巣である, ④再発または遠隔転移を有する, ⑤ 20 歳以上である, ⑥がん告知されている. 除外基準は, ①視覚障害, 日本語の理解が困難なためアンケートに回答できないと考えられる者, ②認知症, 認知障害, 精神疾患, 高齢, 意識障害などによりアンケートを理解する能力がない者, ③身体的苦痛が大きいと考えられる者, ④精神的苦痛が大きいと考えられる者, とした.

3. 遺族調査

対象施設は, 遺族調査への参加同意が得られた 28 病院と 11 診療所とした.

対象者は, 2007 年 4 月〜2008 年 3 月までに, 対象施設で死亡した患者の遺族 (診療記録類に記載されたキーパーソンもしくは身元引受人) のうち, 次の適格基準を満たす者とした. ①患者が調査施設の一般病棟・緩和ケア病棟で死亡, または診療所から在宅診療を受け自宅で死亡した, ②患者が対象地域に居住している, ③患者のがん原発部位が肺, 胃・食道, 肝臓・胆

表1　対象者背景—患者背景

		n	%
性別	男性	138	50.9
	女性	133	49.1
年齢	平均±標準偏差	66.4±11.5	
原発部位	肺	70	25.8
	胃・食道	25	9.2
	肝臓・胆嚢・膵臓	25	9.2
	結腸・直腸	38	14.0
	乳腺	55	20.3
	腎臓・前立腺・膀胱	33	12.2
	子宮・卵巣	20	7.4
	その他	5	1.8
PS	0	76	28.0
	1	121	44.6
	2	55	20.3
	3	9	3.3
	4	4	1.5

表2　対象者背景—遺族背景

		n	%
性別	男性	150	27.3
	女性	396	72.0
年齢	20～39歳	29	5.3
	40～59歳	215	39.1
	60～79歳	281	51.1
	80歳以上	21	3.8
患者との続柄	配偶者	302	54.9
	実子	161	29.3
	その他	84	15.3
患者の性別	男性	346	62.9
	女性	198	36.0
患者の年齢	20～39歳	4	0.7
	40～59歳	70	12.7
	60～79歳	341	62.0
	80歳以上	135	24.5
患者の原発部位	肺	154	28.0
	胃・食道	107	19.5
	肝臓・胆嚢・膵臓	134	24.4
	結腸・直腸	50	9.1
	乳腺	23	4.2
	腎臓・前立腺・膀胱	35	6.4
	子宮・卵巣	16	2.9
	その他	30	5.5
患者の死亡場所	一般病院	367	66.7
	緩和ケア病棟	143	26.0
	在宅	40	7.3

嚢・膵臓, 結腸・直腸, 乳腺, 泌尿器, 子宮・卵巣である, ④患者の入院または在宅診療開始から死亡までの期間が3日以上である, ⑤患者が20歳以上である, ⑥遺族が20歳以上である, ⑦がん告知されている.

2 調査内容

調査は郵送法による自記式質問紙調査によって行われた. 自由回答の質問として「がん治療や苦痛をやわらげる治療に関する地域での改善点や課題につきまして, ご記入いただければ幸いです」と尋ねた. 質問紙の内容は, 患者が受けた医療に対する評価を尋ねるもので, 患者調査の質問数は54問, 遺族調査は75問であった. 調査期間は, 患者調査は2008年4月—7月, 遺族調査は同年10月—12月であった.

3 分　析

調査で得られた回答の内容分析を行った. まず, すべての回答を意味のある文節に区切り, 地域におけるがん治療・緩和ケアに関する内容を抽出した. 同様の内容のものを一般化してサブカテゴリーをつくり, 類似した内容をさらに抽象度の高いカテゴリーとしてまとめ, がん治療・緩和ケアに関する改善点・要望, 良かった点に分類した. 患者調査と遺族調査の内容を比較するために, カテゴリー・サブカテゴリーを統一した (よって, 回答数が0の項目がある). 次に, 2名の看護系学生が独立して, カテゴリー, サブカテゴリーの回答数を全回答から数えた. 2名の結果が異なった場合, 最終的な決定は専門家立ち会いのもとに話し合いで行った. κ係数は, 患者調査0.64, 遺族調査0.58であった.

結　果

患者調査では, 1,493名に調査票が配布され, 859名 (57.7%) から回収されたうち, 自由回答欄に記載があったのは271名 (18.2%) であった. 遺族調査では, 1,658名に調査票が配布され, 1,110名 (66.9%) から回収されたうち, 自由回答欄に記載があったのは550名 (33.2%) であった. 背景を表1, 2に示す.

分析の結果, 地域におけるがん治療・緩和ケアに関する改善点・要望について40のサブカテゴリーが抽出され, これらは「医療システム」「医療スタッフ」「治療」「一般社会におけるがんの認識・緩和ケアの普及」「在宅療養」「苦痛緩和」「家族ケア」「療養場所」「告知」の9カテゴリーにまとめられた (表3). また, 地域におけるがん治療・緩和ケアに関する良かった点について27のサブカテゴリーが抽出され, これらは「医療スタッフ」「苦痛緩和」「家族ケア」「治療」「医療システム」「療養場所」「在宅療養」「告知」の8カテゴリーにまとめられた (表4).

改善点・要望については, 患者調査では, 医療システムに関することが最も回答が多く (50.2%), 中でも「経済的負担を軽減してほしい」(10.3%),「院内システムを改善してほしい」(8.1%) の割合が高かった. そのほかには,「一般市民にホスピス・緩和ケアに関して情報提供してほしい」(10.7%),「十分な苦痛緩和をしてほしい」(9.6%) などの意見が挙げられた. 遺族調査では, 医療スタッフに関することが最も多く (48.2%), 中でも「患者とのコミュニケーションを充実させてほしい」(16.0%),「病状・治療・予後に関して十分な説明をしてほしい」(14.2%) の割合が高かった. その他には,「十分な苦痛緩

表 3　自由回答から得られたがん治療・緩和ケアに対する改善点・要望

項目	患者		遺族	
	n	%	n	%
1. 医療システムに関すること	136	50.2	177	32.2
(1) 経済的負担を軽減してほしい	28	10.3	44	8.0
(2) 院内システムを改善してほしい (外来の待ち時間の短縮, 看護外来の整備, 他科との連携, 時間外診療)	22	8.1	26	4.7
(3) 病院間・地域における連携を改善・強化してほしい (治療中の生活支援, セカンドオピニオン)	17	6.3	24	4.4
(4) 医療の地域差をなくしてほしい	15	5.5	22	4.0
(5) ホスピス・緩和ケアを普及・充実させてほしい (意味の普及, 適応の拡大, 患者の希望を取り入れる, 施設間ケア・対応の均一化)	13	4.8	15	2.7
(6) がん専門医療機関・ホスピス・緩和ケア施設を増設してほしい	11	4.1	12	2.2
(7) 医療スタッフの人材不足・多忙を改善してほしい	9	3.3	11	2.0
(8) 早期発見・早期治療をしてほしい	8	3.0	10	1.8
(9) 病院のアクセスを良くしてほしい	7	2.6	10	1.8
(10) 医療スタッフの移動をなくしてほしい	6	2.2	3	0.5
2. 医療スタッフに関すること	82	30.3	265	48.2
(1) 患者とのコミュニケーションを充実させてほしい	22	8.1	88	16.0
(2) 病状・治療・予後に関して十分な説明をしてほしい	20	7.4	78	14.2
(3) 精神的ケアを充実させてほしい	19	7.0	39	7.1
(4) 医師・看護師に十分な知識・技術を身につけてほしい	13	4.8	30	5.5
(5) 医師・看護師に迅速な対応をしてほしい	5	1.8	21	3.8
(6) 医療スタッフ間で連携して治療にあたってほしい	3	1.1	9	1.6
3. 治療に関すること	70	25.8	122	22.2
(1) 新しい治療法を開発してほしい	19	7.0	27	4.9
(2) 個別性を考慮した治療を行ってほしい (抗がん剤の選択, 内服方法, 治療方法の選択, 延命治療の有無, 代替療法)	14	5.2	24	4.4
(3) 治療法や治療の作用・副作用について情報提供してほしい	12	4.4	18	3.3
(4) 患者・家族主体で治療・病院の意思決定をさせてほしい	9	3.3	13	2.4
(5) 人としての尊厳を尊重した治療・対応をしてほしい	9	3.3	13	2.4
(6) 医療スタッフと話し合って治療法を選択させてほしい	3	1.1	13	2.4
(7) 抗がん剤に対する情報がほしい	3	1.1	8	1.5
(8) 治療法がなくなった患者を見捨てないでほしい	1	0.4	6	1.1
4. 一般社会におけるがんの認識・緩和ケアの普及に関すること	35	12.9	30	5.5
(1) 一般市民にホスピス・緩和ケアに関して情報提供してほしい	29	10.7	18	3.3
(2) がん・ホスピス・緩和ケアに対するマイナスイメージをなくしてほしい	6	2.2	12	2.2
5. 在宅療養に関すること	31	11.4	39	7.1
(1) 在宅医療体制を充実させてほしい	16	5.9	17	3.1
(2) 在宅療養に関して不安がある	7	2.6	9	1.6
(3) 在宅療養に関した情報を提供してほしい	5	1.8	8	1.5
(4) 在宅療養を希望している	2	0.7	4	0.7
(5) 在宅療養 (訪問看護制度, 介護休暇) が一般に広まってほしい	1	0.4	1	0.2
6. 苦痛緩和に関すること	29	10.7	105	19.1
(1) 十分な苦痛緩和をしてほしい	26	9.6	88	16.0
(2) 麻薬に対し誤解・マイナスイメージをなくしてほしい	3	1.1	15	2.7
(3) 緩和ケアとがん治療を並行させてほしい	0	0.0	2	0.4
7. 家族ケアに関すること	15	5.5	48	8.7
(1) 家族の身体的・精神的・社会的・経済的負担を軽減してほしい	15	5.5	37	6.7
(2) 医師・看護師は家族の気持ちも考慮してほしい	0	0.0	11	2.0
8. 療養場所に関すること	12	4.4	48	8.7
(1) 最期はホスピス・緩和ケア病棟で過ごさせてほしい	5	1.8	21	3.8
(2) 末期での療養場所は患者の希望を聞いてほしい	5	1.8	21	3.8
(3) 病院の療養環境を整備してほしい	2	0.7	6	1.1
9. 告知に関すること	1	0.4	14	2.5
(1) 病名告知において患者への精神的配慮をしてほしい	1	0.4	8	1.5
(2) 本人への病名告知はしない方がいい	0	0.0	6	1.1

表 4　自由回答から得られたがん治療・緩和ケアに関する良かった点

項目	患者		遺族	
	n	%	n	%
1. 医療スタッフに関すること	60	22.1	466	84.7
(1) 医療スタッフを信頼・感謝している	41	15.1	240	43.6
(2) 医療スタッフの態度・丁寧な説明が良かった	14	5.2	186	33.8
(3) 医療スタッフのケアが良かった	4	1.5	24	4.4
(4) 医療スタッフ間で連携がとられていた	1	0.4	7	1.3
(5) 個別性をふまえた対応をしてくれた	0	0.0	5	0.9
(6) 医療スタッフが開いてくれる行事が良かった	0	0.0	4	0.7
2. 苦痛緩和に関すること	29	10.7	87	15.8
(1) 十分な苦痛緩和が行われた	29	10.7	87	15.8
3. 家族ケアに関すること	8	3.0	28	5.1
(1) 家族・周囲に感謝している	7	2.6	14	2.5
(2) 家族の事情や負担を考慮した対応をしてくれた	1	0.4	7	1.3
(3) 付き添えたことが良かった	0	0.0	5	0.9
(4) 家族の意思を最後まで聞き入れてくれた	0	0.0	2	0.4
4. 治療に関すること	7	2.6	44	8.0
(1) 十分な治療を行ってくれた	3	1.1	21	3.8
(2) 患者の意思を尊重した治療をしてもらえた	3	1.1	13	2.4
(3) メディアの情報により治療法が決断できた	1	0.4	10	1.8
(4) 患者の QOL を保てた	0	0.0	0	0.0
5. 医療システムに関すること	6	2.2	22	4.0
(1) 早期発見・早期治療が行われた	4	1.5	14	2.5
(2) 同じスタッフが担当してくれて安心した	1	0.4	4	0.7
(3) 保険制度により経済的不安が軽減できた	1	0.4	2	0.4
(4) 病院が状況や希望に応じた対応をしてくれた	0	0.0	2	0.4
(5) 地域の医療システムが充実していた	0	0.0	0	0.0
6. 療養場所に関すること	3	1.1	90	16.4
(1) ホスピス・緩和ケアにプラスイメージを持てた	2	0.7	62	11.3
(2) 患者が希望する場所で過ごせた (自宅, 緩和ケア病棟)	1	0.4	20	3.6
(3) 療養環境が充実していた	0	0.0	8	1.5
7. 在宅療養に関すること	1	0.4	20	3.6
(1) 在宅医療体制が充実している	1	0.4	20	3.6
8. 告知に関すること	0	0.0	6	1.1
(1) 患者に告知せずに亡くなって良かった	0	0.0	2	0.4
(2) 告知時の医療スタッフのサポートが良かった	0	0.0	3	0.5
(3) 亡くなった後の準備が十分にできた	0	0.0	1	0.2

和をしてほしい」(16.0%),「院内システムを改善してほしい」(8.0%) などが挙げられた.

良かった点については, 患者・遺族調査ともに, 医療スタッフに関することが最も多く (患者 22.1%, 遺族 84.7%), 中でも「医療スタッフを信頼・感謝している」(患者 15.1%, 遺族 43.6%) の割合が高かった.

考　察

本研究はわが国の複数地域・複数施設の進行がん患者と遺族から得られた, がん治療・緩和ケアに関する改善点を整理した初めての研究である.

患者・遺族ともに多かった意見として,「患者とのコミュニケーションを充実させてほしい」が挙げられた. がん患者の遺族を対象とした先行研究においても, 医療者とのコミュニケーションは患者の good death のために重要であるという結果が得られており[10], 今回の結果も患者と医療者間のコミュニケーションの重要性を支持する結果となった.

「十分な苦痛緩和をしてほしい」という意見も患者・遺族ともに多く, 苦痛緩和に対するさらなる要望が挙げられた. また,「新しい治療法を開発してほしい」や「個別性を考慮した治療を行ってほしい」など, より新しく, より個人に合った治療が

求められていることも示唆された．

「経済的負担を軽減してほしい」という意見も，患者・遺族ともに上位であった．約1,000人の市民を対象に行った意識調査でも8割が「療養のための費用負担が大きい」と回答しており[11]，療養に関わる経済的負担が生活に大きく影響している現状が示唆された．

本調査の患者調査では「一般市民にホスピス・緩和ケアに関して情報提供してほしい」という意見が多く，進行がん患者に対する緩和ケアの情報が不足している現状がうかがえた．緩和ケアや医療用麻薬については「命を縮める」といった否定的で誤った理解がされている場合もあるため[12, 13]，それらの改善も含めた啓発活動が必要であるといえる．

同じく本調査の患者調査では「院内システムを改善してほしい」「病院間・地域における連携を改善・強化してほしい」という意見も多かった．現状の診療体制の余裕のなさや，病院間の連携の少なさについて，患者が改善してほしいという希望を持っているといえる．

がん治療・緩和ケアに関する良かった点として，患者・遺族ともに医療スタッフへの信頼や感謝の記述が多くみられた．緩和ケア病棟や自宅など，患者の望む場所での十分な緩和ケアが期待されていることが示唆された．

本調査の限界として，質問紙調査の自由記述欄に回答があった対象者のみを対象としているため，自由記述までの回答に至らなかった対象者の意見が反映されていないというバイアスが指摘される．また，筆者はOPTIMに携わり介入の経過を把握しているため，そのことが本研究の分析や考察に影響を与えた可能性は否定できない．

結　語

本研究の結果から，がん患者と遺族は，医療者とのコミュニケーションの充実，苦痛緩和の質の向上，経済的負担の軽減，緩和ケアに関するさらなる啓発活動，医療連携システムの改善，などの要望を持っていることが明らかとなった．また，患者の希望する場所で緩和ケアを受けることができる環境づくりが求められていることが示唆された．これらをふまえた介入を地域に行い，緩和ケア普及のためのモデルづくりを行うことが今後の課題である．

謝辞　本研究は，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対策のための戦略研究「緩和ケア普及のための地域プロジェクト」により行われました．調査実施にご協力いただいた五十嵐歩様，分析にご協力いただいた長澤めぐみ様，笠水上かなえ様，松下田侑里様に心よりお礼申し上げます．

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古村和恵，宮下光令，木澤義之，川越正平，秋月伸哉，山岸暁美，的場元弘，鈴木　聡，木下寛也，白髭　豊，森田達也，江口研二：申告すべき利益相反なし

Rapid Communications

Requests for cancer treatment and palliative care: suggestions from 821 advanced cancer patients and bereaved families

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It is important to collect patients' and their families' opinions to provide good palliative care. This study aims to analyze the contents of free description provided by the survey for cancer patients and bereaved families, which was performed before the intervention of The Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study. Requests for and good points of cancer treatment and palliative care were collected and classified. 1,493 advanced cancer patients and 1,658 bereaved families in four areas received the questionnaire, and 271 patients and 550 families filled in the free description. Cancer patients and bereaved families had demands for improved communication with medical staff, improved quality of pain relief, financial support of treatment, more educational activities on palliative care, and improved cooperation within and outside hospitals.

Palliat Care Res 2011; 6(2): 237-245

Key words: palliative care, content analysis, free description

Table 1　Characteristics of participants—Patients

		n	%
Sex	Male	138	50.9
	Female	133	49.1
Age	Mean age±S.D.	66.4 ± 11.5	
Primary tumor site	Lung	70	25.8
	Stomach, esophagus	25	9.2
	Liver, biliary system, pancreas	25	9.2
	Colon, rectum	38	14.0
	Breast	55	20.3
	Kidney, prostate, bladder	33	12.2
	Ovary, uterus	20	7.4
	Others	5	1.8
PS	0	76	28.0
	1	121	44.6
	2	55	20.3
	3	9	3.3
	4	4	1.5

Table 2　Characteristics of participants—Bereaved families

		n	%
Sex	Male	150	27.3
	Female	396	72.0
Age	20~39	29	5.3
	40~59	215	39.1
	60~79	281	51.1
	80 and over	21	3.8
Relationship with patient	Spouse	302	54.9
	Birth child	161	29.3
	Others	84	15.3
Sex	Male	346	62.9
	Female	198	36.0
Age of patient	20~39	4	0.7
	40~59	70	12.7
	60~79	341	62.0
	80 and over	135	24.5
Primary tumor site of patient	Lung	154	28.0
	Stomach, esophagus	107	19.5
	Liver, biliary system, pancreas	134	24.4
	Colon, rectum	50	9.1
	Breast	23	4.2
	Kidney, prostate, bladder	35	6.4
	Ovary, uterus	16	2.9
	Others	30	5.5
Place of patient death	General hospital	367	66.7
	PCU	143	26.0
	Home	40	7.3

Table 3 Requests for cancer treatment and palliative care

Items	Patients		Families	
	n	%	n	%
1. Medical care system	136	50.2	177	32.2
(1) To reduce financial burden.	28	10.3	44	8.0
(2) To improve hospital system (shortening of the waiting time of outpatient department, maintenance of the nurse of outpatient department, cooperation with other departments, overtime treatment).	22	8.1	26	4.7
(3) To improve and strengthen the cooperation of hospitals in communities (life support during treatment, second opinion).	17	6.3	24	4.4
(4) To alleviate regional disparities in medicine.	15	5.5	22	4.0
(5) To disseminate and improve hospice and palliative care (dissemination of principle, expanding the adaption of care, fulfilling hope of patients, cooperation with other institutions).	13	4.8	15	2.7
(6) To increase cancer center, hospine and PCU.	11	4.1	12	2.2
(7) To alleviate the shortage of medical staff to improve their practices.	9	3.3	11	2.0
(8) To detect and treat cancer in the early stage.	8	3.0	10	1.8
(9) To improve access to hospitals.	7	2.6	10	1.8
(10) To prevent the transfer of medical staff.	6	2.2	3	0.5
2. Medical staff	82	30.3	265	48.2
(1) To communicate with patients sufficiently.	22	8.1	88	16.0
(2) To explain physical condition, treatment and prognosis clearly for patients.	20	7.4	78	14.2
(3) To provide sufficient mental care for patients.	19	7.0	39	7.1
(4) To educate doctors and nurses to obtain suffieient knowledge and technique.	13	4.8	30	5.5
(5) To listen to the needs of patients immediately.	5	1.8	21	3.8
(6) To cooperate with medical staff in different departments.	3	1.1	9	1.6
3. Treatment	70	25.8	122	22.2
(1) To develop new treatment.	19	7.0	27	4.9
(2) To value the individual preferences of patinets in treatment (the choice of anticancer treatment, internal remedy, therapeutic method, life-support treatment and alternative medicine).	14	5.2	24	4.4
(3) To obtain more information about treatment, and the effects and side-effects of medicine.	12	4.4	18	3.3
(4) To discuss and decide treatment in patient/family-centered circumstances.	9	3.3	13	2.4
(5) To receive treatment in dignity.	9	3.3	13	2.4
(6) To decide treatment through discussion with medical staff.	3	1.1	13	2.4
(7) To obtain information about anticancer treatment.	3	1.1	8	1.5
(8) To stay with patients who have no effective treatment.	1	0.4	6	1.1
4. Recognition and dissemination of palliative care in communities	35	12.9	30	5.5
(1) To provide sufficient information about hospice and palliative care for the general public.	29	10.7	18	3.3
(2) To counter negative publicity about hospice and palliative care.	6	2.2	12	2.2
5. Home care	31	11.4	39	7.1
(1) To expand the system of home care.	16	5.9	17	3.1
(2) To relieve concern with the current home care.	7	2.6	9	1.6
(3) To provide information about home care.	5	1.8	8	1.5
(4) I want to choose home care.	2	0.7	4	0.7
(5) To disseminate home care (home nursing, nursing leave) in communities.	1	0.4	1	0.2
6. Pain relief	29	10.7	105	19.1
(1) To relieve pain sufficiently.	26	9.6	88	16.0
(2) To remove the misunderstanding and negative images of drug.	3	1.1	15	2.7
(3) To receive cancer treatment and palliative care collaterally.	0	0.0	2	0.4
7. Family care	15	5.5	48	8.7
(1) To reduce physical, mental, social and financial burden of family.	15	5.5	37	6.7
(2) To educate doctors and nurses toconsider the hearts of family.	0	0.0	11	2.0
8. Place of treatment	12	4.4	48	8.7
(1) To spend last days in hospice or PCU.	5	1.8	21	3.8
(2) To ask for the patient's hope of treatment place.	5	1.8	21	3.8
(3) To improve the medical environment of hospitals.	2	0.7	6	1.1
9. Notice of cancer	1	0.4	14	2.5
(1) To consider the hearts of patients to notice cancer.	1	0.4	8	1.5
(2) Cancer should not be noticed to patients.	0	0.0	6	1.1

Table 4 Good points of cancer treatment and palliative care

Items	Patients		Families	
	n	%	n	%
1. Medical staff	60	22.1	466	84.7
(1) I trust and thank medical staff.	41	15.1	240	43.6
(2) Medical staff was in good manner and gave detailed explanation.	14	5.2	186	33.8
(3) Medical staff provided sufficient care.	4	1.5	24	4.4
(4) Medical staff was in good cooperation each other.	1	0.4	7	1.3
(5) Medical staff provided individual care.	0	0.0	5	0.9
(6) Medical staff planned interesting events.	0	0.0	4	0.7
2. Pain relief	29	10.7	87	15.8
(1) Sufficient pain relief was provided.	29	10.7	87	15.8
3. Family care	8	3.0	28	5.1
(1) I thank my family and acquaintances.	7	2.6	14	2.5
(2) Medical staff counted the condition and the burden of family.	1	0.4	7	1.3
(3) Hospital stay of family was good.	0	0.0	5	0.9
(4) Medical staff granted family's voices.	0	0.0	2	0.4
4. Treatment	7	2.6	44	8.0
(1) Sufficient treatment was provoded.	3	1.1	21	3.8
(2) Treatment respecting the intention of patients was provoided.	3	1.1	13	2.4
(3) I could decide treatment with media information.	1	0.4	10	1.8
(4) The QOL of patients was maintained.	0	0.0	0	0.0
5. Medical care system	6	2.2	22	4.0
(1) Early detection of cancer and early treatment were provided.	4	1.5	14	2.5
(2) The staff in charge provided continuous and comfortable care.	1	0.4	4	0.7
(3) Financial burden was decreased by insurance.	1	0.4	2	0.4
(4) Individual support was provided in hospital.	0	0.0	2	0.4
(5) The local system of medicine was substantial.	0	0.0	0	0.0
6. Place of treatment	3	1.1	90	16.4
(1) I could have positive images of hospice and palliative care.	2	0.7	62	11.3
(2) The patient could stay in the preffered place (Home, PCU).	1	0.4	20	3.6
(3) Treatment environment was substantial.	0	0.0	8	1.5
7. Home care	1	0.4	20	3.6
(1) The system of home care was substantial.	1	0.4	20	3.6
8. Notice of cancer	0	0.0	6	1.1
(1) The notice of cancer was not provided preferably.	0	0.0	2	0.4
(2) Support to receive the notice of cancer was well provided.	0	0.0	3	0.5
(3) Preparation after death was well organized.	0	0.0	1	0.2

JOURNAL OF PALLIATIVE MEDICINE
Volume 14, Number 8, 2011
© Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2010.0529

Public Awareness, Knowledge of Availability, and Readiness for Cancer Palliative Care Services: A Population-Based Survey across Four Regions in Japan

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Abstract

Background: This study explores the distribution of public awareness, knowledge of availability, and readiness for palliative care services, and the perceived reliability of information resources as part of a nationwide palliative care implementation intervention in Japan (Outreach Palliative Care Trial of Integrated Regional Model [OPTIM]).

Methods: A cross-sectional anonymous questionnaire survey was conducted, and 3984 responses were used in the final analysis.

Results: A total of 63.1% of respondents admitted having no knowledge about palliative care, while 0.5% of respondents were using palliative care services. Respondents who knew about palliative care services, yet did not know about their availability were 18.6% of all respondents. Respondents who had cancer-related experiences were more likely to be aware of palliative care compared to the general population and availability of palliative care services. Only awareness of palliative care was significantly associated with two typical images, while cancer-related experiences were not.

Conclusion: Findings show that the public awareness of palliative care services and their availability is insufficient, and cancer-related experiences affect awareness of cancer palliative care but not directly related to typical images for palliative care such as care for patients close to death.

Introduction

Palliative care for patients with cancer in Japan has rapidly progressed in the past decade, but many critical issues still need to be resolved. To improve overall cancer care (including palliative care) throughout Japan, the Cancer Control Act was established in April 2007. To facilitate the dissemination of palliative health services, the Ministry of Health, Labour, and Welfare focuses on palliative care concerns, and has launched a multiple nationwide project for community-based intervention trials in four areas in Japan, as described via the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study.[1] The study includes creating community-based specialized palliative care teams, developing educational materials, educating community medical staff on palliative care, and campaigning to disseminate knowledge relevant to specialized palliative care programs to patients, families, and the general public.

The reason that this trial includes the campaign is that the general public does not have adequate knowledge about palliative care concepts.[1] For example, only 34% of the general population knows about palliative care units in Japan, whereas the rate of knowledge in the United Kingdom is 70%.[2,3] Of note, although 32% of the Japanese general public

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Accepted March 28, 2011.

believes that palliative care units are places where patients simply wait for death, these misperceptions are significantly decreased after individuals actually use a specialized palliative care service.[3,4] Thus, the lack of knowledge and general misperceptions regarding palliative care are considerable barriers to palliative care and appropriate pain control, and further education of the general public would be of great value.

This research has revealed prevalence and relationships among general knowledge and perceptions for barriers but has not clarified intentions, acceptance, and knowledge of the availability if the people use the services in a local region. To develop effective strategies to promote the enhanced utilization of palliative care services, we must explore the demographics (such as gender, age, or residential status) and barriers related to not only general public awareness of palliative care, but also intention for use, knowledge of the availability, and actual rate of service utilization. As the previous study revealed,[3,4] it is also expected that opinions of palliative care, which are supposed to be formed from personal experiences, affected not only general awareness but intention or readiness. In particular, sources to form opinions of cancer palliative care are supposed to be cancer-related experiences as the patient themselves or as the patient's family members.[5]

This article, therefore, has the following aims: (1) to clarify the distribution of public awareness, knowledge of availability, and readiness for palliative care services, (2) to clarify the differences in awareness, knowledge, and readiness among demographic variables and between healthy individuals and those who have cancer-related experiences (either personally or via family), (3) to clarify the differences of typical opinions of palliative care in awareness, knowledge, and readiness, in relation to cancer-related experiences and other demographics.

Methods

Subjects

This study was a part of OPTIM, and the overall protocol has been provided in detail elsewhere.[1] Our investigation was a survey of the general population, including patients with cancer and their families in four regions from the OPTIM study. These consisted of a large urban area (Chiba), an urban area (Shizuoka), and two rural areas (Nagasaki and Yamagata). The first three areas are places in which palliative care services are available and the last one (Yamagata) is, in comparison, a location in which services are practically unavailable.

A cross-sectional anonymous questionnaire survey was conducted in a sample of the general population selected by stratified two-stage random sampling in each area (2,000 subjects in each of four regional areas). As a result, this sample included cancer patients (outpatients receiving or having received cancer treatment). We mailed a total of 8,000 questionnaires to these potential participants in June 2007 and on a later date sent a reminder postcard. On the questionnaire, we explained the aim of the study and regarded completion and return of the questionnaire as consent for participation in this study. The institutional review boards of Tokyo University confirmed the ethical and scientific validity.

Questionnaire

We developed our own questionnaire on the basis of the aims of OPTIM and through literature reviews, existing surveys, and consensus among the authors as follows. On the cover page of the questionnaire, palliative care was defined as: attempts to make patients with cancer and their family less anxious or to experience less pain, to immediately start consultations about anxiousness and pain regardless of the state of cancer development, and in addition to treatment, to facilitate the teamwork of doctors and nurses in the practice of treating patients who are suffering from the physical and/or emotional effects of cancer.

The questionnaire included three parts. First, it included questions covering the demographic information of the subjects (age, gender, length of living in each area) and whether subjects are undergoing (or had undergone) cancer treatment or had family members who had experiences of undergoing cancer treatment. Second, it included an item originally designed to determine the extent of public awareness, knowledge of availability, and readiness and actual utilization of palliative care service. We asked the participants to choose only one option from six sequential options regarding palliative care and such services: (1) no knowledge (I have no knowledge regarding palliative care; I); (2) lack of knowledge of availability (I have heard of palliative care, but I do not know if there are any available facilities in my municipality; II); (3) no interest (I know about palliative care and its availability in my residential area, but I have no interest in the service; III); (4) no intention (I know about palliative care and its availability in my residential area, and have an interest, but I have no intention of using the service as a patient or for a family member; IV); (5) preparation (I am preparing to use palliative care services; V); (6) under utilization (I currently use palliative care services; VI; Fig. 1). We converted the subjects' responses for these responses (I to VI) into a numeric

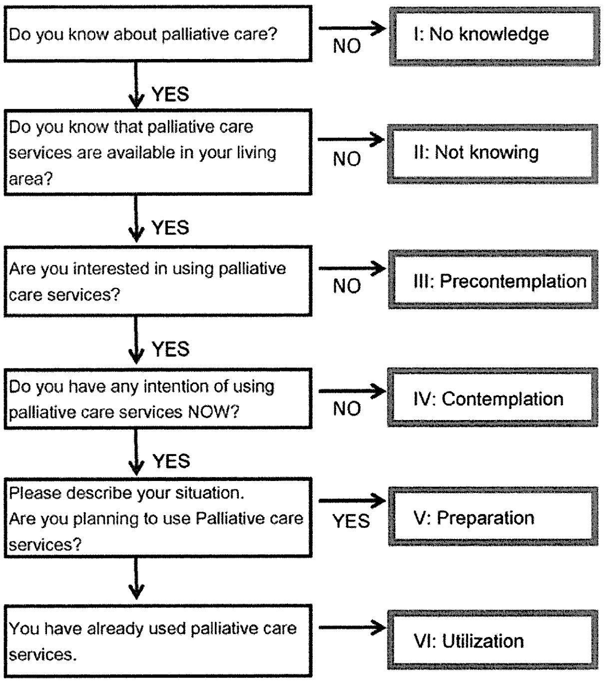

FIG. 1. Public awareness and readiness for palliative care services.

TABLE 1. DEMOGRAPHIC BACKGROUND OF THE RESPONDENTS

	Total		*General population*		*Those who have experienced cancer*	
	(n = 3190)		*(n = 1330)*		*(n = 1860)*	
	n	%	n	%	n	%
Age years						
40–49	705	22.1	302	22.7	403	21.7
50–59	1020	32.0	404	30.4	616	33.1
60–69	898	28.2	385	28.9	513	27.6
70-	567	17.8	239	18.0	328	17.6
Gender						
Male	1,426	44.7	666	50.1	760	40.9
Female	1,764	55.3	664	49.9	1100	59.1
Region (Prefecture)						
Chiba	945	29.6	413	31.1	532	28.6
Shizuoka	785	24.6	364	27.4	421	22.6
Nagasaki	733	23.0	274	20.6	459	24.7
Yamagata	727	22.8	279	21.0	448	24.1
Length of living in each area						
<1 year	38	1.2	22	1.7	16	0.9
1–5 year	131	4.1	60	4.5	71	3.8
>5 year	3,021	94.7	1,248	93.8	1,773	95.3

scale ranging from 1 to 6 points. Finally, three items related to palliative care beliefs/concepts ("Palliative care relieves pain and distress"; "Palliative care is used with chemotherapy and radiotherapy"; "Palliative care is for patients close to death.")[3,5] were presented, and responses were measured on a five point Likert-type scale from 1) strongly disagree to 5) strongly agree.

Analysis

Descriptive analyses were carried out summarizing the subjects' backgrounds, awareness of palliative care and utilization of such services, and scores for reliable media source opinions for total and each sampled area. Then we explored the distribution of knowledge and readiness of palliative care and utilization of the service associated with each sampled area and experiences of having cancer. These analyses were performed after dividing subjects into two groups (the general population and cancer patients/survivors) and we used the χ^2 test and Cramer's V to clarify relations between categorical variables and using coefficient correlation and relations between two categorical variables and ordered variables two-way analysis of variance (ANOVA). We conducted all statistical analyses using the Statistical Package for the Social Sciences (version 15.0.1.1J, SPSS Inc., Chicago, IL) software package. The significance level was set at $p < 0.05$ (two-tailed).

Results

Of the 8000 questionnaires delivered to the sampled subjects, 26 were returned as undeliverable and 3984 were returned (response rate, 49.8%). Of those returned, 3190 were considered valid for statistical analyses. The rest ($n = 794$) were invalid and were excluded from the analyses since major information was lacking. Thus, the final rate of valid replies was 39.9%.

A total of 1860 respondents (58.3% of all respondents) were identified as "those having experienced cancer" and the rest were identified as belonging to the "general population." Table 1 summarizes the background of respondents.

Public awareness, knowledge, and readiness for palliative care

A total of 63.1% of respondents admitting to having "no knowledge" of palliative care while 0.5% of respondents were actually using palliative care services. Respondents who knew about palliative care yet did not know about the availability of palliative care in their living area were 18.6% of all respondents. Female respondents were more likely to know about palliative care than male respondents ($\chi^2 = 55.09$, $df = 1$, $p < 0.001$, Cramer's V = 0.131), while age and length of living in each area were not significantly associated with

TABLE 2. PUBLIC AWARENESS AND READINESS FOR PALLIATIVE CARE SERVICES

	Total		*General population*		*Those who have experienced caner*		*Chiba*		*Shizuoka*		*Nagasaki*		*Yamagata*	
	(n = 3190)		*(n = 1330)*		*(n = 1860)*		*(n = 945)*		*(n = 785)*		*(n = 733)*		*(n = 727)*	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
I: No knowledge	2012	63.1	909	68.3	1,103	59.3	546	57.8	518	66.0	482	65.8	466	64.1
Having Knowledge	1178	36.9	421	31.7	757	40.7	399	42.2	267	34.0	251	34.2	261	36.0
II: Not knowing	593	18.6	230	17.3	363	19.5	201	21.3	96	12.2	115	15.7	181	24.9
III: Not interseted	24	0.8	13	1.0	11	0.6	5	0.5	12	1.5	5	0.7	2	0.3
IV: No Intention	499	15.6	167	12.6	332	17.8	171	18.1	142	18.1	116	15.8	70	9.6
V: Preparation	46	1.4	10	0.8	36	1.9	18	1.9	14	1.8	10	1.4	4	0.6
VI: Under Utilization	16	0.5	1	0.1	15	0.8	4	0.4	3	0.4	5	0.7	4	0.6

Cancer experience×Awareness (No knowledge vs. Having knowledge): $\chi^2 = 27.24$, $df = 1$.
$p < 0.01$, Cramer's V = 0.092.
Four areas×Awareness (No knowledge vs. Having knowledge): $\chi^2 = 16.83$, $df = 3$, $p < 0.01$, Cramer's V = 0.073.
Within People who Knew Palliative Care:
Cancer experience×Availability: $\chi^2 = 4.83$, $df = 1$, $p < 0.028$, Cramer's V = 0.064
Four areas×Availability: $\chi^2 = 61.88$, $df = 3$, $p < 0.01$, Cramer's V = 0.229.
Availability: No awareness of availability vs. awareness of availability.

either awareness, knowledge or readiness. Respondents who had cancer-related experiences (either themselves or via family members) were more likely to be aware of palliative care compared to the general population ($\chi^2 = 27.24$, $df = 1$, $p < 0.001$, Cramer's V = 0.092). Also among people who knew palliative care, there was a significant association between cancer experience and knowledge for availability or readiness ($\chi^2 = 4.83$, $df = 1$, $p = 0.028$, Cramer's V = 0.064). Table 2 also shows that awareness and knowledge of and readiness for palliative care was significantly different among each area ($\chi^2 = 16.84$, $df = 3$, $p < 0.001$, Cramer's V = 0.073). Particularly, respondents in Chiba-city have more knowledge about palliative care than individuals from the other three areas.

Typical images of palliative care

Table 3 indicates the results of two-way ANOVA for responses on three typical images of palliative care using awareness and cancer experiences as dependent variables, when age, gender, and area were controlled. First, the analysis revealed the differences in perception for three common images of palliative care between individuals having no knowledge of palliative care and those who had knowledge. Significant differences were observed between them in terms of images of palliative care in the following dimensions: "Palliative care relieves pain and distress" (general population; $F(1, 3186) = 33.02$, $p < 0.001$, Those having experienced cancer; $F(1, 3186) = 60.85$, $p < 0.001$) and "Palliative care is for patients close to death" (general population; $F(1, 3186) = 13.62$, $p < 0.01$, Those having experienced cancer; $F(1, 3186) = 13.00$, $p < 0.01$). People who know about palliative care have an overall positive image of it, tend to think that palliative care brings symptom control to the patients, and is specialized for terminally ill patients. There were no significant differences between the general population and cancer-experienced individuals on the three typical opinions of palliative care, and there were no significant interactions between cancer experience and knowledge of palliative care.

TABLE 3. MEAN SCORES OF IMAGES OF PALLIATIVE CARE BY AWARENESS AND EXPERIENCE OF CANCER

Awareness	*General population*						*Those who have experienced cancer*						*Main effect*					
Experience of Cancer	*Total*		*No knowledge*		*Having knowledge*		*Total*		*No knowledge*		*Having knowledge*		*Exp. Cancer*		*Awareness*		*Interaction*	
	M	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	F	p	F	p	F	p
Palliative care relieves pain and distress	3.81	0.80	3.72	0.83	4.00	0.70	3.88	0.85	3.76	0.88	4.06	0.76	2.75	.07	74.73	.00	0.08	.78
Palliative care is used with chemotherapy and radiotherapy	3.51	0.90	3.53	0.85	3.47	1.00	3.51	0.97	3.50	0.94	3.52	1.02	0.18	.68	0.04	.85	1.09	.30
Palliative care is for patients close to death	3.19	1.22	3.12	1.12	3.34	1.26	3.22	1.29	3.15	1.27	3.32	1.30	0.01	.91	15.30	.00	0.36	.55

The results by two-way analysis of variance (ANOVA) were shown when age, gender, and area were controlled as covariates.

Discussion

This study is the first attempt to understand the public awareness of palliative care and utilization of services based on a nationwide sample in Japan. A clarification of these findings will hopefully contribute to understanding general perception of cancer palliative care and its variations by experiences related to cancer.

The primary aim of this study was to clarify the distribution of public awareness, knowledge of availability, and readiness for palliative care services. Per the results of the survey, 63.1% of all the participants had no knowledge of palliative care services. These results demonstrate a low public awareness of the Japanese palliative care services compared with other countries.[2,3] Moreover, among those who did possess knowledge about palliative care in general, 18% did not know about the specific availability of the service in their region. These results indicate that over 80% of people do not have sufficient knowledge of palliative care to take advantage of its services, and it is therefore important to promote a more comprehensive understanding of palliative care (including availability) to the general population.

Second, our data clarified that cancer experiences were related to a greater knowledge of and readiness for palliative care, but did not significantly relate to specific images commonly associated with palliative care. From our data it is difficult to strictly compare patients with cancer with the overall population since the sample surveyed in this study was from the general population, and therefore only a small number of patients with cancer were included. However, people who had experiences with cancer (either personally or via family members) recognized both the term and meaning of palliative care. Also, people who had knowledge of palliative care have an overall positive image of it, tend to think that palliative care brings symptom control to the cancer patients, and is specialized for terminally ill patients. Generally, as the images will be reinforced by actual experiences, those who experienced as patients with cancer or as family members might see or hear the care at late stage of the cancer process. This indicated current situation that palliative care for patients with cancer in general Japanese hospitals was mainly provided for late-stage cancer and that contributed to form the general opinions of palliative care. Also, the perception that palliative care is primarily for terminally ill patients care may cause late referrals to palliative care services.[5,6] These suggest that images derived from actual experiences will have strong impact for actual decision making for choosing or readiness for the services when the patients need. Therefore, it is important to provide proper and detailed information about palliative care services, as well as information regarding the availability of services, within areas of residence. We still have very big challenges to modify the general perception of cancer palliative care, because there is no known effective method to achieve this. Educational approaches in community may become one of the solutions, and will especially be needed to help people recognize that palliative care services accept even patients with early-stage cancer.

This study has several limitations. First, this study did not include measurements for the effectiveness of each medium and we cannot discern which media sources and what kind of information directly led individuals to be more aware of palliative care and to use these services. Second, we did not explore the possible associations between the awareness of palliative care and amounts of actual cancer treatment undergone. A more detailed survey will need to be conducted in order to clarify the above items. Moreover, it would be useful to better explore the insights of specific populations. In future surveys, it should be possible to design more directed questionnaires to support hypothesis-based studies.

In conclusion, the public awareness of palliative care services and their availability is insufficient. Those with cancer experiences were more aware of palliative care and their availability than the general population. Only people who were aware of palliative care developed two typical images, while those with cancer-related experiences did not. Approaches to inform the general population (including those with cancer-related experiences) about palliative care have already been taken in Japan. However, more effective methods should be developed. We feel that it is possible to eliminate many existing barriers to the improvement of end-of-life quality, and the dissemination of knowledge related to such care and treatment in Japan should be a top priority.

Author Disclosure Statement

No competing financial interests exist.

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Knowledge, beliefs, and concerns about opioids, palliative care, and homecare of advanced cancer patients: a nationwide survey in Japan

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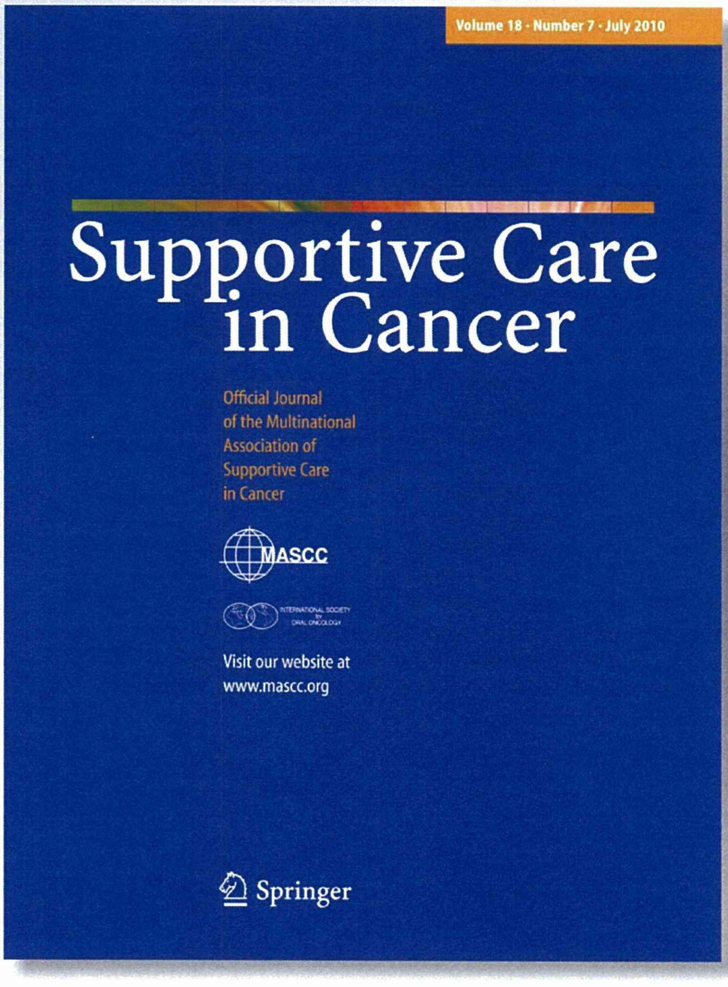
Supportive Care in Cancer

ISSN 0941-4355

Support Care Cancer
DOI 10.1007/
s00520-011-1161-5



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ORIGINAL ARTICLE

Knowledge, beliefs, and concerns about opioids, palliative care, and homecare of advanced cancer patients: a nationwide survey in Japan

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Received: 20 October 2010 / Accepted: 4 April 2011

Abstract

Purpose Patients' knowledge, beliefs, or concerns about opioids, palliative care, and homecare can be potential barriers to providing quality palliative care. The primary aim of this study was to clarify knowledge about opioids, beliefs about palliative care, and concerns about homecare in advanced cancer patients.

Methods An anonymous questionnaire was sent to 1,619 outpatients with advanced cancer at 25 hospitals in four different regions of Japan. The respondents were asked to report their knowledge about opioids, beliefs about palliative care, and concerns about homecare, in addition to the levels of their sense of security regarding receiving cancer care in the region.

Results A total of 925 responses were received. In total, 28% believed that opioids are addictive and/or shorten life; 52% believed that palliative care is only for terminally ill patients; 75% agreed that being taken care of at home puts a heavy burden on the family; and 61% agreed that home-visit services cannot respond to sudden changes in a patient's condition. Levels of patients' sense of security were significantly higher in those who agreed that "opioids can relieve most pain caused by cancer" "palliative care relieves pain and distress", "palliative care is provided along with chemotherapy and/or radiation therapy", and "pain can be alleviated as effectively through home-visit services as it can at the hospital", and those who disagreed with the statements that "home-visit services cannot respond to sudden changes in a patient's condition" and "being taken care of at home puts a burden on the family".

Conclusions Advanced cancer patients frequently had incorrect knowledge about opioids, a belief that palliative care is only for terminally ill patients, and concerns about homecare, especially the family burden and responses to sudden changes. Providing appropriate information about the safety of opioids, the availability of palliative care

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during the entire course of the disease, and realistic information about homecare is of marked importance to promote patients' sense of security.

Keywords Cancer · Palliative care · Homecare · Knowledge · Opioids

Introduction

The numerous barriers to quality end-of-life care are related to patients, families, medical professionals, and the health care system itself [1]. Among them, multiple empirical studies have identified knowledge, beliefs, or concerns about opioids, palliative care, and homecare in the general population and cancer patients as potential barriers for quality palliative care [2–19]. Many surveys have shown that incorrect knowledge about cancer pain and opioids could interfere with optimal pain management, especially an unrealistic fear of addiction and life-shortening [2–7]. Negative beliefs about palliative care were also one of the significant determinants of the potential underuse of specialized palliative care services [8–12]. Moreover, many patients have concerns and difficulties about homecare, such as the burden on the family, concerns about sudden changes in physical conditions, and the unavailability of physicians visiting their home, and these could influence patients' decisions regarding whether or not to receive homecare [13–19].

These findings indicate that providing appropriate information is of marked importance to achieve optimal palliative care, but, to our best knowledge, no large systematic large survey has been performed to clarify the knowledge about opioids, beliefs about palliative care, and concerns about homecare in a representative sample of advanced cancer patients.

In addition, a sense of security is being acknowledged as a very important concept for cancer patients and their families [20–23]. The sense of security is evaluated from the perspective of patients living in a region, and these perspectives reflect the quality of the regional system for providing healthcare services and awareness among the population of the services provided by the system. Funk and colleagues indicated that a feeling of security consisted of trust in competent professionals; timely access to necessary care, services, and information; and a sense of their own identity and self-worth as caregivers and individuals [20]. Despite the increasingly perceived importance of the concept of a sense of security, to date, no empirical studies have measured sense of security levels in advanced cancer patients, and explored the potential association between the levels and patients' knowledge, beliefs, and concerns.

The primary aim of this study was therefore to clarify the knowledge about opioids, beliefs about palliative care, and concerns about homecare in advanced cancer patients. Secondary aims included: (1) to clarify the levels of a sense of security, (2) to explore factors associated with knowledge, beliefs, and concerns, and (3) to explore the potential associations between the levels of a sense of security and knowledge about opioids, beliefs about palliative care, and concerns about homecare.

Subjects and methods

A cross-sectional study was performed by sending questionnaires to consecutive outpatients with metastatic or recurrent cancer in four regions of Japan. This survey was part of the pre-intervention measurements collected for the regional intervention trial, the Outreach Palliative Care Trial of Integrated Regional Model study, and the study's methodology is reported in detail elsewhere [24]. The ethical and scientific validity of this study was confirmed by the institutional review board of the Japan Cancer Society, as well as by those of all participating hospitals (protocol registration number, UMIN000001274 of the University hospital Medical Information Network Clinical Trials Registry).

Participating hospitals

Four study regions were chosen for intervention studies to cover a variety of areas with different palliative care systems across Japan: Tsuruoka (population 170,000, Yamagata Prefecture), Kashiwa (population 670,000, Chiba prefecture), Hamamatsu (population 820,000, Shizuoka Prefecture), and Nagasaki (population 450,000, Nagasaki Prefecture). Kashiwa and Hamamatsu, which are relatively large urban cities, have specialized hospital palliative care teams in a cancer center and general hospitals, respectively; Nagasaki has a coordinated palliative care system for home patients in addition to hospital palliative care teams; and

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Tsuruoka, which is a typical rural town, had no formal specialized palliative care service at the time of survey.

Due to the lack of an established method to identify all cancer patients living in a specific area in Japan, we identified all hospitals in the study areas with reference to hospital lists from the Japan Hospital Association, the largest authorized organization of hospitals in Japan, and local resource information. Of the 54 hospitals identified, we excluded 20 hospitals primarily treating psychiatric, rehabilitation, and geriatric non-cancer patients. We approached the remaining 34 hospitals (11,033 beds), and a total of 23 hospitals (8,964 beds, 81%) participated in this survey: 3 hospitals (Tsuruoka), 7 hospitals (Kashiwa), 8 hospitals (Hamamatsu), and 5 hospitals (Nagasaki).

Patients

Inclusion criteria for patients in this study were: (1) adult cancer patients with a primary tumor site in the lung, esophagus, stomach, colon, rectum, pancreas, liver, biliary system, kidney, prostate, bladder, breast, ovary, or uterus; (2) presence of metastatic or recurrent cancer; (3) outpatient visits to the hospital between April and June 2008; and (4) disclosure of malignancy. Exclusion criteria included: (1) incapacity of the patient to complete the questionnaire (dementia, cognitive failure, or psychiatric illness), (2) severe emotional distress of the patient as determined by the principal treating physician, (3) poor physical condition unable to complete the questionnaire, and (4) language difficulty or visual loss. Patients were recruited consecutively, with hospitals either sending each eligible patient a questionnaire by mail or delivering it directly by hand to the patient.

Measurements

Data were collected on: (1) knowledge about opioids, beliefs about palliative care, and concerns about homecare; (2) sense of security; (3) pain intensity; and (4) patient-perceived quality of palliative care. The questionnaire (available from the authors) was constructed based on an extensive literature review, expert consensus among the authors, and a previous study [2–23, 25–27].

Knowledge about opioids, beliefs about palliative care, and concerns about homecare

We asked the respondents to rate the extent to which they agreed with the statements about their knowledge of opioids, beliefs about palliative care, and concerns about homecare on a 5-point Likert-type scale (1 strongly disagree, 2 disagree, 3 unsure, 4 agree, 5 strongly agree) [2]. Knowledge about opioids was examined using two items: “opioids can relieve most pain caused by cancer” and “opioids are addictive and/or shorten life”. Beliefs about palliative care were examined using three items: “palliative care relieves pain and distress”, “palliative care is provided along with chemotherapy and/or radiation therapy”, and “palliative care is only for terminally ill patients”. Concerns about homecare were examined based on five items: “pain can be alleviated as effectively through home-visit services as it can at the hospital”, “home-visit services cannot respond to sudden changes in a patient’s condition”, “it is hard to find home-visiting physicians”, and “being taken care of at home puts a burden on the family”.

Sense of security about cancer care in the region

The sense of security was measured using the five-item scale to assess feelings of support and security about cancer care in a region [23]. The statements were: (1) “I would feel secure in receiving cancer treatment”, (2) “my pain would be well-relieved”, (3) “medical staffs will adequately respond to my concerns and pain”, (4) “I would feel secure as a variety of medical care services are available”, (5) “I would feel secure in receiving care at home”. We asked participants to rate their level of agreement with the statements on a 7-point Likert scale (1 strongly disagree, 2 disagree, 3 slightly disagree, 4 not sure, 5 slightly agree, 6 agree, 7 strongly agree). The total score of five items, ranging from 5 to 35, quantifies the levels of the sense of security; a higher score indicates higher sense of security levels. Factor validity was established based on the emergence of one factor by explanatory factor analysis, and a high Cronbach’s alpha coefficient (0.91) demonstrated sufficient internal consistency. Criterion-related validity established a significant difference among the total scores of general populations from several areas with various health care services in Japan.

Pain intensity

Pain intensity was measured using the Japanese adaptation of the Brief Pain Inventory, with a score given for the pain at its worst (0–10), at its least (0–10), and a score for the average pain felt (0–10) in the previous 24 h [25]. Its reliability and validity in Japanese populations has been established [25]. For this study, average pain was used for analyses.

Patient-perceived quality of palliative care

Patient-perceived quality of palliative care was measured using the Care Evaluation Scale [26, 27]. The Care Evaluation Scale is a well-validated and commonly used measurement tool in Japan to quantify the level of patient or family-perceived need for improvements in palliative care. The full version of the Care Evaluation Scale consists of eight subscales (three items for seven domains and two