



Support for Patients and Family Caregivers in Lung Cancer

Educational Components of an Interdisciplinary Palliative Care Intervention

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Consistent with the recommendations of the Institute of Medicine Report on quality cancer care, attention to symptom management and quality of life concerns of patients with lung cancer should be addressed throughout the disease trajectory. As part of an National Cancer Institute-funded Program Project grant, this article reports on the patient and family caregiver education component of a nurse-lead, tailored, palliative care intervention for patients with early-stage (I-III, n = 130) and late-stage (IV, n = 142) lung cancer. Patients and family caregivers received 4 separate educational sessions organized around the Quality of Life model domains (physical,

psychological, social, and spiritual well-being). Each patient and caregiver was presented at a weekly interdisciplinary case conference, which also informed the educational sessions. Based on needs and team suggestions, an individualized palliative care plan was created and a tailored educational intervention was designed based on topics chosen by each participant. The most common topics chosen by patients in each domain were fatigue, worry and fear, social support/isolation, and hope. Family caregivers most commonly chose fatigue, worry and fear, communication, and purpose and meaning in life. The time spent in each teaching session ranged from 31 to 44 minutes for patients and 25 to 35 minutes for family caregivers. There is a vital need for interdisciplinary palliative care interventions for patients across all stages and across the disease trajectory. Nurses are vital to integrating palliative care into routine care. Providing a tailored educational intervention is an important aspect of palliative care for patients and family caregivers. This article focuses on the process of the tailored educational intervention.

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Lung cancer is the leading cause of cancer deaths in the United States, and most patients will die of the disease.¹ The estimated 5-year survival for all stages is 16.8%.² Over the past decade, much progress has been made in the areas of screening, treatment, supportive care measures, and symptom management.³⁻⁵ Unfortunately, patients with non-small cell lung cancer (NSCLC) still experience higher symptom burden than those with other solid tumors, as well as psychosocial and spiritual concerns.⁶⁻¹⁵

Results from 2 prominent, randomized controlled trials demonstrated that palliative care interventions provided in conjunction with standard oncology care early in the



disease course improved quality of life (QOL), mood, and symptom burden.^{16,17} Project ENABLE, (Educate, Nurture, Advise Before Life Ends), conducted by Bakitas and colleagues,¹⁶ tested the effects of a nurse-led psychoeducational intervention with 161 patients with advanced cancer. The nurse provided 4 weekly educational sessions by telephone and monthly follow-up sessions, until death or study completion. Compared with patients receiving usual oncology care (n = 161), the nurse-led intervention had higher scores for QOL and mood. Temel and colleagues¹⁷ tested the efficacy of integrating palliative care with standard oncology care for ambulatory patients (n = 151) newly diagnosed with metastatic NSCLC. Results indicated that early palliative care significantly improved the patient's QOL and mood compared with those receiving standard care.

Organizations such as the American Society of Clinical Oncologists have issued statements regarding the need to integrate palliative care into standard oncology care at the time of diagnosis,¹⁸ and other investigators have also supported the integration of palliative care into routine oncologic care of the lung cancer patient across all stages.^{2,19-23}

The authors of this article conducted a National Cancer Institute-funded program project grant to test the efficacy of an interdisciplinary palliative care intervention, including patient assessment and teaching by nurses. The nurses directly involved in this study are advanced practice nurses in oncology with extensive experience in providing patient and caregiver education. In addition, 8 weeks of practice teachings was conducted so that all nurses were adequately familiar with the flow and content of the materials. This article reports on the process of a tailored patient and family caregiver (FCG) educational intervention component of the study. Quantitative outcomes will be forthcoming as data are published.

METHODS

Sample

Study participants with primary lung cancer were recruited from an National Cancer Institute-designated comprehensive cancer center medical oncology outpatient clinic. The participants met the following criteria: (1) primary NSCLC; (2) receiving treatment with chemotherapy, radiation, or combined modalities; (3) 18 years or older; (4) live within a 50 mile radius of the hospital; and (5) no previous cancer within the past 5 years. Family caregivers were identified by asking the patient to designate the 1 person most involved in his/her care.

Educational Intervention

Patients meeting study criteria were approached during a regularly scheduled clinic visit. Written informed consent was obtained before study participation. Upon consent, patients were provided an educational notebook.

The nurse created an interdisciplinary palliative care plan summarizing demographics, patient- and FCG-identified key problem areas, and supportive care needs. Using the interdisciplinary palliative care plan, the nurse presented a comprehensive assessment of both the patient and the FCG at the weekly Interdisciplinary Team (IDT) meetings. Members of the team included the treating oncologist or surgeon, geriatrician, nurse, and key supportive experts in social work, nutrition, pulmonary and physical rehabilitation, pain and palliative medicine, psychology, and chaplaincy. The focus of the IDT meeting was on interdisciplinary support for both the patient's and the FCG's physical, psychological, social, and spiritual well-being. Team members made palliative care recommendations for both the patient and the FCG which were then incorporated into the plan of care. After the IDT meeting, the nurse contacted the patient and FCG to set up the first of 4 educational sessions (Table 1).

Patient Education

The patient education notebook was divided into 4 sections based on the QOL model²⁴: physical, psychological, social, and spiritual well-being domains. Within each section, a list of symptoms or topics was provided, from which the patient chose 3. The lists were based on the authors' previous research^{21,25-28} and the National Comprehensive Cancer Network guidelines for NSCLC.²⁹ At the desired date, time, and location, the nurse either called or saw the patient in the clinic for the educational session. On the basis of the symptoms or topics chosen, the nurse then tailored the education to the patient's needs. During each session, patients were encouraged to ask questions or make comments. Patients then set goals for each symptom or topic discussed and with help from the nurse, decided on actions to accomplish those goals. At the end of the session, the patient was asked 2 to 3 review questions to assess learning. Depending on whether the teaching took place in person or over the telephone, the Action Plan was given to the patient, mailed, or scanned and e-mailed for placement in his/her education notebook. A date and time were then set for the next education session.

At the beginning of the next session, the nurse reviewed with the patient the previous session's goals to assess progress and/or problems before starting the current education session. A debriefing form was used to log the date, patient distress level, those present in addition to the patient, overall impression of the session, location, and total time. This same format was used for all 4 education sessions. Follow-up telephone calls were conducted between questionnaire time points to check on patient concerns, answer questions, and coordinate needed resources.

FCG Education

The FCG educational process mirrored the patient process. The care plan, however, focused on the FCG's supportive



TABLE 1 Palliative Care Intervention Teaching Content	
Patient Teaching	Family Caregiver Teaching
Physical well-being	
Breathing problems	General information on caregiving for the patient's physical symptoms
Cough	Breathing problems and cough
Pain	Pain
Constipation	Constipation
Fatigue	Fatigue
Sleep problems	Sleep problems
Nausea/Vomiting	Nausea and vomiting
Appetite problems	Appetite problems/weight loss
Skin, nail, hair changes	Skin, nail, hair changes
Smoking cessation	Smoking cessation
	Caring for your own health needs
Action plan	Self-care plan
Psychological well-being	
Worry and fear	General information on caring for the patient's emotional needs
Depression	Worry and fear
Anger	Depression
Cognitive changes	Anger
	Cognitive changes
	Caring for your own emotional needs
Action plan	Self-care plan
Social well-being	
Changes in relationships	General information on caring for the patient's social concerns
Communication	Changes with relationships
Sexual changes	Communication
Social support	Sexual changes
Financial burden	Social support
Health care planning (advance directive)	Financial burdens

Continued

TABLE 1 Palliative Care Intervention Teaching Content, Continued	
Patient Teaching	Family Caregiver Teaching
	Health care planning (advance directive)
	Caring for your own social needs
Action plan	Self-care plan
Spiritual well-being	
Spiritual or religious	General information on caring for the patient's spiritual concerns
Purpose and meaning in life	Purpose and meaning in life
Hope	Hope
Redefining self and priorities in life	Redefining self and priorities in life
Inner strength	Inner strength
Uncertainty	Uncertainty
Positive changes	Positive changes
	Caring for your own spiritual needs
Action plan	Self-care plan

care needs and included QOL needs, caregiver burden, and preparation for caregiving. The 4 teaching sessions were also based on the 4 QOL domains and focused on common symptoms faced by families and patients dealing with lung cancer. During each session, the FCG picked 3 symptoms in the QOL domain, the choices guiding the content of the teaching session. Second, in each session, the nurse assisted the FCG in developing a self-care plan, with the caregiver identifying a self-care goal and determining activities to achieve that goal. Caregiver self-care included exercise, nutrition, managing one's own health, healthy living recommendations, and external support. Supportive care referrals were initiated based on recommendations from the IDT and the FCG's expressed needs. Periodically, the nurse conducted follow-up evaluations, reassessed caregiver needs, and revised the care plan.

RESULTS

Demographics

Table 2 summarizes the intervention group patient demographics. Early stage (stage I-III) comprised 47.8% of the patients and late stage (stage IV), 52.2%. Most patients were non-Hispanic (93%) and female (63.6%). Sixty-percent of the patients were 65 years or older and 79.8% were white,



TABLE 2 Patient Demographics	
Stage groupings	
Early stage (stage I-III)	130 (47.8%)
Late stage (stage IV)	142 (52.2%)
Age	
<65 y	109 (40.1%)
65-74 y	100 (36.8%)
≥75 y	63 (23.2%)
Sex	
Male	99 (36.4%)
Female	173 (63.6%)
Ethnicity	
Hispanic/Latino	19 (7.0%)
Non -Hispanic/Latino	253 (93.0%)
Race	
American Indian/Alaska Native	0 (0%)
Asian	32 (11.8%)
Black or African American	14 (5.1%)
Native Hawaiian or other Pacific Islander	7 (2.6%)
White (Includes Latino)	217 (79.8%)
More than 1 race	2 (0.7%)
Education completed	
Elementary school	2 (0.7%)
Secondary/high school	93 (34.2%)
College	177 (65.1%)
Marital status	
Other (single, separated, widowed, divorced)	101 (37.3%)
Married/partnered	170 (62.7%)
Live alone	
No	216 (79.4%)
Yes	56 (20.6%)
Employment	
≥32 h/wk	235 (86.4%)
<32 h/wk	37 (13.6%)

Continued

TABLE 2 Patient Demographics, Continued	
Religion	
Protestant	109 (40.1%)
Catholic	76 (27.9%)
Jewish	14 (5.1%)
Muslim	1 (0.4%)
Buddhist	2 (0.7%)
None	47 (17.3%)
Other	23 (8.5%)
Income	
≤\$50 000	93 (34.3%)
>\$50 000	135 (49.8%)
Prefer not to answer	43 (15.9%)
Smoking history	
Current smoker	16 (5.9%)
Former smoker	186 (68.4%)
Nonsmoker	70 (25.7%)
Treatments	
Chemotherapy	199 (73.2%)
Surgery	76 (27.9%)

with most having completed college (65%). Most patients were married (62%), did not live alone (79.4%), and worked at least 32 hours a week (86%). Protestant was the predominant religion (40%), more than half had an annual income greater than \$50 000 (49.8%), and most were former smokers (68.4%). Seventy-three percent received chemotherapy. Table 3 summarizes the FCG demographics. Fifty-seven percent of the FCG participants were late stage, and 43% were early stage. Mean age was 57.4 years, and the sample was predominantly female (60.6%). Most FCGs were non-Hispanic (87.7%), completed college (72.4%), and were married/partnered (76.7%). Seventy-six percent worked less than 32 hours a week, with most (60.6%) having an income of more than \$50 000 per year. Most FCGs were Protestant (40.1%) or Catholic (27.7%), and most were non-smokers (55.7%).

Intervention Results

Table 4 provides the mean length of time spent teaching the educational topics offered to the patient and FCG within each QOL domain. The most frequently chosen



TABLE 3 Family Caregiver Demographics

Stage groupings	
Early stage (stage I-III)	157 (43%)
Late stage (stage IV)	209 (57%)
Age, y	
Range	18-88
Median	57.5
Mean	57.4
Sex	
Male	80 (39%)
Female	123 (60.6%)
Ethnicity	
Hispanic/Latino	24 (11.8%)
Non-Hispanic/Latino	178 (87.7%)
Race	
American Indian/Alaska Native	0 (0%)
Asian	16 (7.9%)
Black or African American	5 (2.5%)
Native Hawaiian or other Pacific Islander	10 (4.9%)
White (includes Latino)	167 (82.3%)
Other	5 (2.5%)
Education completed	
Elementary school	1 (0.5%)
Secondary/high school	55 (27.1%)
College	147 (72.4%)
Marital status	
Other (single, separated, widowed, divorced)	47 (23.2%)
Married/partnered	156 (76.7%)
Live alone	
No	85 (92.6%)
Yes	15 (7.4%)
Employment	
≥32 h/wk	48 (23.6%)

Continued

TABLE 3 Family Caregiver Demographics, Continued

<32 h/wk	52 (76.4%)
Religion	
Protestant	81 (40.1%)
Catholic	56 (27.7%)
Jewish	16 (7.9%)
Muslim	0 (0%)
Buddhist	1 (0.5%)
Other/none	44 (21.8%)
Income	
≤\$50 000	39 (19.2%)
>\$50 000	123 (60.6%)
Prefer not to answer	41 (20.2%)
Smoking history	
Current smoker	15 (7.4%)
Former smoker	75 (36.9%)
Nonsmoker	113 (55.7%)

topics by patients within each QOL domain are provided in Table 5. Fatigue (69%) and pain (36%) were the 2 most selected topics regardless of disease stage in the physical well-being domain, followed by breathing and sleep problems (32% each), constipation (29%), appetite problems/weight loss (25%), and cough (22%). Worry and fear (81%) was the predominant topic chosen within the psychological well-being domain. Within the social well-being domain, social support/isolation (65%) and communication (50%) were the most common topics chosen, followed by changes in relationships (44%) and advance directive planning (39%). Hope (72%), inner strength (64%),

TABLE 4 Time (in minutes) Spent in Teaching Sessions

Session Type	Patient, Mean	Family Caregiver, Mean
Physical	43.7	34.8
Psychological	36	27.8
Social	31.1	25.5
Spiritual	32.4	25



TABLE 5 Patient Intervention Education Topics Selected Physical, Psychological, Social, and Spiritual Well-Being

Quality of Life Domain	Early-Stage Patients (n = 123)		Late-Stage Patients (n = 122)		Total (N = 245)	
	n	% of Cases	n	% of Cases	n	% of Cases
Physical well-being						
Fatigue	93	76%	75	63%	168	69%
Pain	60	49%	29	24%	89	36%
Breathing problems (dyspnea)	37	30%	42	35%	79	32%
Sleep problems	45	37%	33	27%	78	32%
Constipation	38	31%	34	28%	72	29%
Appetite problems/weight loss	34	28%	28	23%	62	25%
Cough	16	13%	37	30%	53	22%
Skin, nail, hair changes	5	4%	39	32%	44	18%
Nausea and vomiting	15	12%	18	15%	33	13%
Other	26	21%	–	–	26	11%
Psychological well-being						
Worry and fear	105	85%	94	77%	199	81%
Depression	59	48%	72	59%	131	53%
Cognitive changes	9	7%	72	59%	81	33%
Anger	18	15%	37	30%	55	22%
Other	12	1%	–	–	12	1%
Social well-being						
Social support/isolation	97	79%	62	51%	159	65%
Communication	53	43%	69	57%	122	50%
Changes in relationships	44	36%	64	52%	108	44%
Health care planning (advanced directive)	14	11%	82	67%	96	39%
Financial burdens	26	21%	33	27%	59	24%
Sexual changes	20	16%	15	12%	35	14%
Other	6	4%	–	–	6	0.2%
Spiritual well-being						
Hope	110	89%	67	55%	177	72%
Inner strength	103	84%	55	45%	158	64%

Continued



TABLE 5 Patient Intervention Education Topics Selected Physical, Psychological, Social, and Spiritual Well-Being, Continued

Quality of Life Domain	Early-Stage Patients (n = 123)		Late-Stage Patients (n = 122)		Total (N = 245)	
	n	% of Cases	n	% of Cases	n	% of Cases
Uncertainty	92	75%	43	35%	135	55%
Purpose and meaning in life	28	23%	42	34%	70	29%
Positive changes	4	0.3%	57	47%	61	25%
Redefining self and priorities	10	8%	45	37%	55	22%
Spiritual or religious	13	11%	9	7%	22	9%
Other	4	3%	–	–	4	0.1%

and uncertainty (55%) were chosen most frequently in the spiritual well-being domain.

Table 6 provides the FCGs' most frequently chosen topics within each QOL domain. Even more so for the FCG, fatigue (74%) was the most predominant physical domain topic. Worry and fear (88%) and depression (58%) were the most requested topics for psychological domain, followed by anger (42%) and cognitive changes (41%). For social well-being, communication (78%) and advance directive planning (61%) were the most common topics. Roughly half of the FCGs chose purpose and meaning (54%), hope (49%), and inner strength (49%) as the main topics for spiritual well-being.

DISCUSSION

Lessons Learned

Patients

When the intervention was initiated, patients received 4 educational sessions as detailed in the patient education notebook. Over time, many patients requested to either reduce the 4 sessions to 2 by combining them or combine all 4 sessions into 1. This was more conducive if they were not feeling well, and to their schedule. In addition, most patients with late-stage (stage IV) lung cancer wanted their teaching conducted via telephone. This provided privacy and the opportunity to be comfortable at home and avoided an extra trip to the hospital, an interruption during a busy clinic visit while getting chemotherapy, or having to stay beyond their clinic appointment. Early-stage lung cancer patients (stages I-III) preferred to receive their education sessions while they were inpatients, while recovering from surgery, or during their chemotherapy infusion. Most late-stage patient caregivers were not present during the education session because most all sessions took place

over the telephone. The opposite was true for early-stage patient caregivers. Having brought the patient to the appointment, they listened in on the session. Being flexible to meet the patients' and FCGs' needs was key to continued study participation.^{30,31}

Another lesson learned was that although patients desired supportive services recommended during the teaching, such as physical therapy/occupational therapy or pulmonary rehabilitation, some were physically unable to make extra trips to the hospital if the appointment was not on their scheduled clinic day. According to previous research, this is not uncommon, as patients struggle with logistical issues such as taking time off work, child care, transportation, and costs.^{32,33} In addition, patients who did not feel well, and those who felt better, also tended to cancel or fail to attend their appointments.³³ Patient symptoms made it very difficult, if not impossible, for patients to follow through on required exercises. This was mainly the case for late-stage lung cancer patients. Most early-stage lung cancer patients refused supportive care services. The 2 most common reasons were feeling that they did not need it and associating palliative care with end of life.

Patients appreciated the action plan because it put their goals in writing and served to remind them of what was discussed during the education session. It also provided a means for patients to self-manage aspects of their illness and life; this is supported by previous research as well as the Institute of Medicine's 2003 report, *Priority Areas for National Action: Transforming Health Care Quality*.^{34,35} Patients did not always have 3 applicable topics. In that case, they chose a topic they wanted to learn more about. For example, if a patient stated he/she had constipation but it was well controlled, the nurse asked the patient to share how he/she was controlling the symptom. As the patient shared, the nurse was provided an opportunity to affirm the patient's actions. From there, the patient focused on those actions to remain



TABLE 6 Family Caregiver Intervention Education Topics Selected Physical, Psychological, Social, and Spiritual Well-Being

Quality of Life Domain	Early-Stage Caregivers (n = 65)		Late-Stage Caregivers (n = 72)		Total (N = 137)	
	n	% of Cases	n	% of Cases	n	% of Cases
Physical well-being						
Fatigue	55	85%	46	64%	101	74%
Pain	31	48%	22	31%	53	39%
Appetite problems/weight loss	28	43%	24	33%	52	38%
Breathing problems/cough	21	32%	29	40%	50	36%
Sleep problems	23	35%	12	17%	35	26%
Nausea/vomiting	18	28%	14	19%	32	23%
Constipation	12	18%	13	18%	25	18%
Skin, nail, hair changes	–	–	14	19%	14	10%
Swelling	–	–	8	11%	8	6%
Diarrhea	–	–	7	10%	7	5%
Other	5	7%	–	–	5	4%
Psychological well-being						
Worry and fear	59	91%	34	47%	121	88%
Depression	37	57%	42	58%	79	58%
Anger	34	52%	23	32%	57	42%
Cognitive changes	28	43%	28	39%	56	41%
Other	5	1%	23	32%	28	20%
Social well-being						
Communication	60	92%	47	65%	107	78%
Health care planning	35	54%	49	68%	84	61%
Changes in relationships	44	68%	32	44%	76	55%
Social support	38	58%	30	42%	68	50%
Financial burden	12	18%	9	12%	21	15%
Sexual changes	9	14%	4	.05%	13	1%
Other						
Spiritual well-being						
Purpose and meaning	35	54%	39	54%	74	54%

Continued



TABLE 6 Family Caregiver Intervention Education Topics Selected Physical, Psychological, Social, and Spiritual Well-Being, Continued

Quality of Life Domain	Early-Stage Caregivers (n = 65)		Late-Stage Caregivers (n = 72)		Total (N = 137)	
	n	% of Cases	n	% of Cases	n	% of Cases
Hope	30	46%	37	51%	67	49%
Inner strength	45	69%	22	31%	67	49%
Redefining self and priorities	38	58%	15	21%	53	39%
Positive changes	32	49%	6	1%	38	28%
Uncertainty	11	17%	22	31%	33	24%
Other						

constipation free. Many patients appreciated the affirmation and were relieved to hear they were doing the right thing. Some patients found that creating goals gave them something to look forward to. For example, 1 patient was too fatigued to meet friends for lunch and never knew how she would feel on any given day, so she invited a friend to her home who offered to bring lunch. This provided a way for her to socialize yet balance rest and activity. Other patients who set goals were unable to accomplish these because of physical symptoms. One example was a gentleman who was feeling well and asymptomatic and had planned a weekend getaway from “all things hospital” to have time alone with his wife. Several days before leaving for the trip, he experienced side effects from targeted therapy, preventing him from taking the trip.

Family Caregivers

Many lessons learned in providing educational sessions to the FCGs were similar to those learned in providing patient education. Sessions were often combined in the interest of caregiver time and schedule. The session length and topic depended on the caregiver’s needs and priorities. Whereas some caregivers preferred the sessions at the time the patient was receiving treatment, most preferred telephone sessions, when they were free of work and caregiving responsibilities. Privacy and time to focus on one’s own needs were highly valued. The number of sessions done at 1 time and the amount of time per session varied according to caregiver needs.

Family caregivers spent time in each session discussing and learning symptom management strategies in each QOL domain, focusing on problems caregivers or their loved ones were experiencing while living with lung cancer. Often, the symptom management discussion focused on effective strategies the caregiver was already using, with additional symptom management techniques pointed

out during the session and available in the written material. Although patient and caregiver symptom management was included in each session, greater focus was placed on the patient’s symptoms when discussing the QOL physical domain. Teaching and reinforcing techniques to manage the patient’s physical symptoms helped the caregiver feel better prepared for caregiving, positively impacting the caregiver’s QOL. The FCGs spent a greater amount of time on self-care during the educational sessions in the psychological, social, and spiritual domains.

Family caregivers found creating a self-care plan that defined goals and actions to maintain or improve personal QOL to be helpful. The importance of attending to one’s own needs while caring for a loved one with a life-threatening illness is often forgotten. When a caregiver identified actions in 1 QOL domain while creating a self-care plan, he/she often identified the same actions in other domains. For example, an FCG might identify taking a 30-minute walk twice a week with the next-door neighbor as an action in the QOL physical, emotional, social, and spiritual domains. The overall effect of creating a self-care plan was to help the caregivers remember what they do to care for themselves while they are busy caring for others. Keeping it simple while addressing individual styles and needs was paramount.

One of the most important lessons learned in teaching and intervening with FCGs of lung cancer patients was the value of attending to and providing resources to meet the caregiver’s needs while providing an open line of communication with the nurse/health care provider. In a question asking caregivers if there is anything specific they would like to be better prepared for, many FCGs expressed a profound level of uncertainty because they did not know what would be required of them in their caregiving role. Some stated they did not even know what questions to ask. They valued having a connection with the nurse providing the education sessions as they faced an uncertain future.



CONCLUSIONS AND IMPLICATIONS FOR NURSING

Interdisciplinary palliative care interventions are vital for patients with lung cancer across the disease trajectory. Given the high distress levels of both patients and caregivers living with lung cancer, it is important to provide an education tailored to individual needs by allowing them to set the priorities. The tailored education used in this study is generalizable for other clinical nurses with oncology and palliative care experience. Nurses are in a unique role to help integrate palliative care into routine care.

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