

ORIGINAL RESEARCH

COPD-Patients adherence to care and quality of counseling

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ABSTRACT

Objective: The aim of this study was to describe Chronic Obstructive Pulmonary Disease (COPD) patients' adherence to care and to identify quality of counseling in tertiary care. The objective was to improve the quality of care of COPD patients and receive baseline information factors which improve their adherence to care. Background: It has been reported that the treatment of patients with COPD may not be optimal. It is also known that COPD-patients have various limitations in daily life due their disease, and may experience emotional distress, which can reduce adherence to care.

Methods: The data were collected during COPD-patients' (n = 141) visits or admissions to a tertiary hospital between November 2007–June 2009. This study was cross-sectional survey and the data analysed by descriptive statistics, averaged variables and multivariate regression analysis.

Results: The response rate was 62%. Most of patients were men and they have been COPD patients for several years. Nearly all patients were adherent to their care and medication, but support from health care providers was inadequate. Counseling had been benefit about half of COPD-patients and it increased self-care activities and coping at home. Counselling was not implemented in a patient-centred way and mutual goal setting was insufficient. Multidisciplinary counseling and quality care transition were both significantly factors with adherence to care and the support of the health care providers.

Conclusions: The patient with COPD adhere well to care, but support health care providers were in adequate. Multidisciplinary team and high quality counseling is crucial, although in practice delivery is not always appropriate for the patient.

Key Words: Adherence, COPD, Disease-management, Nursing care, Counselling, Patient education

1. INTRODUCTION

It has been reported that patients with Chronic Obstructive Pulmonary Disease (COPD) may not be optimally treated.^[1-3] The patient's own assessments of their illness burden are correlated to coping with daily life.^[4,5] The ignoring patients' experiences in care decisions or their views about care improvements have also influence on patients'

adherence.^[6] This paper is intended add to knowledge of COPD hospital patients' perceptions of their counseling of illness, adherence to care and management affecting the effectiveness of care.

COPD is an inflammatory disease associated with comorbidity such as diabetes, depression. Self-management is crucial, complex and demanding in coping with COPD. It in-

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cludes monitoring, assessing and interpreting the symptoms of the disease, including co-morbidities, making decisions and using pharmacological and non-pharmacological strategies in order to stabilise the condition.^[1] COPD has a major impact on the patients' physical and emotional functions such as self-blame, shame and guilt because of their smoking history.^[7] They were also feeling of being discriminated and lack of social support because of self-inflicted disease.^[5,8] Patients' self-image can be altered^[1] and negative experiences can result in additional strain and burden to the patient, thus increasing depressive symptoms.^[8,9] Experiences of self-blame can prevent patients avoiding seeking help and both negative physical and emotional responses.^[10]

The most common distressing symptoms associated with COPD are breathlessness and fatigue, which limit the patient's activities of daily life.^[5,11] Breathlessness can be frightening and frustrating, its may led to social isolation.^[12] Fatigue in daily life decreases mobility, which has a negative impact on daily activities and performance.^[13] Some patients ponder about the continuation of life and the loss of the ability to continue to lead life as before.^[14] Poor knowledge and symptom management are related to uncertainty.^[5,15] According to Ryyänänen^[14] the experiences of meaningful life associated with illness-management decreases the feeling of insecurity. Depression, anxiety, fear^[16,17] and disability contribute to poor adherence to care, negative effects on treatment outcomes^[18] and compromised well-being. Depression and anxiety can result in non-adherence and vice versa.^[9]

In this study, adherence is defined as an active, intentional and responsible process of care, in which the individual works to maintain his or her health in close collaboration with their health care providers.^[19-22] It is also defined as a partnership in care, involving patients in decision-making to improve adherence with care requirements. The concept emphasises a high quality mutual relationship between the patient and the care provider. Several factors are associated with adherence such as factors related to patients; health care providers; the disease; and the environment.^[17] Patient's personal attributes, knowledge, skills and experiences can be used to predict adherence.^[23] Knowledge is a pre-deposition for adherence and involvement in care but knowledge of disease does not guarantee adherence.^[24,25] Skills related to adherence include a patient's self-management, problem-solving skills and decision-making.^[26] Patient's previous experience, feelings, beliefs and preferences, self-efficacy or making sense of things^[5,27] will shape their adherence.^[23] In addition, the patient's sense of normality, jadedness in care and positive therapeutic responses are connected to adherence.^[19,22,25,28] Factors related to care providers that contribute to adherence include the health care provider's

personal attitudes^[24] and ability to engage in active interaction with the patient.^[3,17,23,29] Social support provided by health care providers can greatly contribute to patient adherence.^[17,19,22,25,28] Also, systematically implemented multi- and inter-disciplinary^[4,30] working in health care^[24,27] increases adherence. The aim of this study was to describe COPD patients' adherence to care and to identify quality of counseling in tertiary care. The objective was to identify baseline information factors which improve patients' adherence to care and improve quality of care for patient with COPD.

2. METHOD

Data were collected using non-experimental sampling, a cross-sectional survey. A questionnaire was distributed to COPD-patients' (n = 141), during their visits or admissions to the three pulmonary care units of the northern tertiary hospital between November 2007–June 2009.

After discharge COPD-patients who fitted the criteria were by a staff nurse, whether they would participate in the study. Inclusion criteria and exclusion for participation were stated orally and in written form. The patients of terminal care, acute lung cancer or life-threatening myocardial infarction, or memory disorders were excluded from the study. Each respondent returned the survey to a locked mailbox when leaving the clinic or sent it to the researcher using a pre-paid envelope. The postal option was preferred by most respondents.

2.1 Data collection

Adherence was measured using The Adherence Scale (AS) and the quality of counseling was measured using The (Counselling Quality Instrument [CQI], version 2003). In addition, participants' demographics details and their perceptions of the quality of care transition using The Care Transitions Measure (CTM-3[®]) were recorded. In total, there were 50 original survey items.

The demographics collected were: sex, age, date of COPD diagnosis, education, co-morbidities, previous visit to the hospital, staying or visiting in the hospital, delivery of counseling by health care professionals, smoking history, use of an electronic respiratory assistance device and demonstration of the inhalation technique during the visit or stay.

Adherence to Care (AC)^[20,25] was measured by the five averaged variables in AS: adherence to medication; responsibility in care; a sense of normality; perceived support by relatives and support by health care providers. The relevant survey section contained 21 variables; the responses all required ranking using a five-point Likert scale. Twenty items were

used in the analysis.

The CQI^[29,31,32] covers four main areas; “content of counseling”, “implementation of counseling”, “benefit of counseling” and “counseling materials and methods”. In this study was used “implementation of counseling” and “benefit of counseling”. “Implementation of counseling” include four averaged variable components: mutual goal-setting; atmosphere during counseling; dialogue within the counseling; and patient-centred implementation. In addition, the “benefit of counseling” (BC) include three averaged variables: patients’ perceptions of their increased positive mood; self-care activities; and coping at home. The CQI contained 17 variables and the BC 9 variables. All of the items required ranking on a five-point Likert-scale.

The CTM-3[®] assessed the quality of care transitions (QCT).^[33] The measure is consistent with the concept of patient-centeredness, and can be used for performance measurement. The survey contained three five-point Likert-scale variables: accounting for the patient’s opinions about care transition; awareness of managing one’s health; and administering medication at home.

2.2 Ethical considerations

Permission to use the original scales was granted by the copyright holders. The approval of the hospital clinical director was obtained before conducting the survey. In Finland, according to the Medical Research Act (488/1999, and amendments 295/2004), this type of study does not require a statement of opinion by an ethics committee. The participants were informed by a letter attached to the questionnaire that their answers would be used in this study and refusal would not affect their care. The researcher would consider the information confidential. All participants provided written informed consent. The study conforms to the principles outlined in the Declaration of Helsinki. The visual appearance of the survey was designed to account for the patients’ age as far as possible; font size 14, emboldened text and the outlined boxes were used. The survey was seven pages long.

2.3 Data analysis

There were random missing answers and these were accounted for by using values of multiple imputations derived using the Predictive Mean Matching algorithm.^[34] Three imputed data sets were analysed, and estimates were made for the pooled data. Scale ratings were examined using a Kolmogorov-Smirnov test. In the data analysis, the demographic, nominal and Likert-scale items were re-coded. First, in the AS, negative items were turned into positive ones, so that the variables reflected trends in the same direction. The five-point Likert scale used in the AS, CQI and CTM-3[®]

ranged from “totally agree” to “totally disagree”, with the alternative “do not know”. The five-step Likert in the BC ranged from “an extremely high level of benefit” to “no benefit at all”. The high scores in the AS, CQI (CQI and BC) and CTM-3[®] components reflected a high positive perception (“agreed” or “a high level of benefit” indicate a positive response and “disagreed” or “no benefit” a negative response).

Next, the Likert variables were made sum-variables. In the AS, the five-point Likert classification of the averaged variables was 1.0-3.00 and 3.01-5.0 (two categories). In the CQI and CTM-3[®] the five-point Likert classification of the averaged variables was 1.0-2.49, 2.50-3.49 and 3.50-5.0 (three categories). All the classifications were based on the ratings used before or on the scale distribution analysis of the data. All data analysis was performed using PASW (Predictive Analytics SoftWare) 18.0.3.

Descriptive statistics, averaged variables, Binary Logistic, Multinomial and Ordinal Logistic regressions were used^[34,35] with a complementary log-log link function in order to analyse the connection between the predictors, which were the demographic variables and the responses which were the averaged variables of AC, quality of counseling (CQI and BC) and QCT. The averaged variables were also used as predictors when connections between them and the main outcome responses, AC. In addition, the connections between CQI and perceived BC were explored. The number of background variables was 11.

The scale of the re-coded dependent variables determined the use of specific multivariate statistics. The reference category was specified as “Last” for the predictors of the Binary Regression and as “First” for the dependent variables of the Multinomial Regression, based on logical reasoning. All the variables in a certain part of the survey (demographic variables and the averaged variables of AS, CQI and CTM-3[®]) were used in the regression analysis in turn rather than to improve the regression model systematically. The number of averaged variables used as the predictors was five in the AS and CQI, three in the BC and one in the CTM-3[®]. The demographic variables was used as the predictors in the Binary Regression model. The level of significance was set at $p \leq .050$ (two-tailed), and 95% confidence intervals (C.I.) were calculated for EXP(B).

2.4 Validity and reliability of the instruments

The translation procedure for the CTM-3[®] was robust. The questions were translated from English to Finnish and back again. The translation procedure and explanations relating to the linguistic decisions were sent back to the copyright-holder for checking (CTM-3[®]). The usability, intelligibility

and feasibility of the survey items were pre-tested by three COPD-patients, one healthy elderly person, four clinical nurses and two nursing scientists for content validity. Some linguistic changes were made as a result, mainly concerning words or expressions to improve comprehensibility. The results of this and previous studies can be used to measure external reliability (stability) of the tools (e.g. Coleman,^[33]

Yamada^[36]). In addition, the results can be used to explore the correlation validity with the values obtained. The coefficients of internal reliability (the level of the targeted acceptance was set $> .60$) of the averaged variables are presented in Table 1. Cronbach's alpha coefficients are the computed means of the five imputed data coefficients.

Table 1. The coefficients of internal reliability of the averaged variables and the survey components of instruments

Averaged variable	Number of items	Range	Cronbach's alpha
Total: Adherence to care (AC)	20	0-4	.709
Adherence to medication	3	0-4	.121
Responsibility to care	5	0-4	.406
Sense of normality	5	0-4	.530
Support by relatives	4	0-4	.552
Support by health care providers	3	0-4	.610
Total: Benefits of counselling (BC)	9	1-5	.831
Increase in positive mood	3	1-5	.616
Increased self-care activities	4	1-5	.673
Coping at home	2	1-5	.681
Total: CQI	17	0-5	.914
Atmosphere during counselling	3	0-5	.766
Mutual goal-setting	3	0-5	.686
Patient-centeredness	3	0-5	.649
Dialogic implementation	8	0-5	.823
Total: QCT	3	0-5	.580

3. RESULTS

In this study the response rate was 62%. Three-quarters of the participants were male (70%) with COPD diagnosed many years ago (70%). About half of the participants (54%) were under 65 years of age and used an electronic respiratory aid apparatus (52%) (oxygen concentrator, ventilator or electronic inhalation device). Most of the participants (82%) had co-morbidities and over one-third (35%) of them were admitted to hospital as an in-patient. Forty percent of the participants were not asked to demonstrate their ability to use their home inhaler when staying at the hospital or during their clinical referral. Forty-one percent of the participants smoked. Over half of the participants (53%) reported that counseling was provided either by the doctor or the nursing staff (not both) during the hospital visit or stay (see Table 2).

Nearly all participants (97%) considered themselves to be adherent to care (AC). However, about a third of the participants (31%) reported that they did not receive support from the health care providers during their stay or visit to hospital (see Table 3). There were only a few participants (3%) who respond not to be responsibility self-care and 16% of partic-

ipants have a problematic feeling about sense of normality. Most of participants (83%) receive support their relatives (see Table 3).

The participants (46%) considered that counseling had some benefit (BC) when provided at the hospital. 48% of them reported that counseling had some positive benefit on their mood, whilst sixteen percent said it had no or hardly any positive effect. The participants (27%) reported that, counseling facilitated their ability to cope at home or led to an increase in self-care activities (34%). Delivery of quality of counseling was reported by 30% of participants. 28% of participants did not agree with the targets set as part of counseling and disagreed (37%) that the implementation was patient-centred. The participants (63%) gave a positive assessment of QCT. However 37% of participants did not know or disagree quality of care transition (see Table 3).

Participants considered counseling ($p = .044$), care transition ($p = .031$) and atmosphere ($p = .030$) to be of higher quality when the nursing staff and the medical doctor delivered counseling together. However, none of these dependent

variables were statistically significant when the significance level was set at $p \leq .01$. It should be noted that when participants stated that the nursing staff and the medical doctors delivered counseling together, the support from the health care providers was considered to be very significantly better than when they delivered counseling on their own ($p = .006$). There was also a weak correlation, although not significant, showing that participants who received counseling in the form of the preferred and active self-care training responded positively with respect to adherence ($p = .073$). When participants reported that their care transition (CT) was of high quality, there was a highly significant correlation with reports of increased support from the care providers and adherence ($p = .018$) (see Table 4).

Table 2. The demographic details of participants (n=141)

Demographic variables	n	%
Sex^{*)}		
Male	98	(70)
Female	43	(30)
Age^{*)***)}		
< 65 years	76	(54)
≥ 65 years	65	(46)
COPD diagnosed^{*)}		
Recently	42	(30)
Many years ago	99	(70)
Education^{*)}		
Basic Education	92	(65)
Vocational Education	49	(35)
Co-morbidities^{*)}		
Yes	116	(82)
No	25	(18)
Previous visit to hospital (year)		
≤2008	80	(57)
2009	61	(43)
Staying or visiting		
In-patient	49	(35)
Out-patient	92	(65)
Smoking		
Yes	58	(41)
No	83	(59)
Use of the electronic respiratory assistance device		
Yes	73	(52)
No	68	(48)
Inhaler use demonstrated		
Yes	70	(50)
No	57	(40)
Do not remember	14	(10)
Delivery of counselling		
MD and RN together	53	(38)
MD or RN alone	75	(53)
No counselling	13	(9)

*) Demographic data gathered previously; **) Mean: 64 years
 ***) Range: 35-85.

Table 3. Perceived adherence to care (AC) and benefit of counseling (BC) in COPD participants (n=141)

Variables	n	%
Adherence to care (AC) (total averaged variable; 20 items)		
Yes	137	(97)
No	4	(3)
Adherence to medication (averaged variable; 3 items)		
Yes	122	(87)
No	19	(13)
Responsibility to care (averaged variable; 5 items)		
Yes	137	(97)
No	4	(3)
Sense of normality (averaged variable; 5 items)		
Yes	119	(84)
No	22	(16)
Support by relatives (averaged variable; 4 items)		
Yes	117	(83)
No	24	(17)
Support by health care providers (averaged variable; 3 items)		
Yes	97	(69)
No	44	(31)
Benefit of counselling (BC) (total averaged variable; 9 items)		
Poor	13	(9)
Satisfactory	65	(46)
Good	63	(45)
Increase in positive mood (averaged variable; 3 items)		
Poor	23	(16)
Satisfactory	67	(48)
Good	51	(36)
Increased self-care activities (averaged variable; 4 items)		
Poor	13	(9)
Satisfactory	48	(34)
Good	80	(57)
Coping at home (averaged variable; 2 items)		
Poor	15	(11)
Satisfactory	38	(27)
Good	88	(62)
Quality of counselling (CQI) (total averaged variable; 17 items)		
Disagreed or no counselling provided	22	(16)
Do not know	76	(54)
Agreed	43	(30)
Atmosphere during counselling (averaged variable; 3 items)		
Negative atmosphere or no counselling provided	27	(19)
Do not know	46	(33)
Positive atmosphere	68	(48)
Mutual goal-setting (averaged variable; 3 items)		
Disagreed or no counselling provided	39	(28)
Do not know	51	(36)
Agreed	51	(36)
Patient-centeredness (averaged variable; 3 items)		
Disagreed or no counselling provided	52	(37)
Do not know	55	(39)
Agreed	34	(24)
Dialogic implementation (averaged variable; 8 items)		
Disagreed or no counselling provided	26	(18)
Do not know	62	(44)
Agreed	53	(38)
Quality of care transition (QCT) (total averaged variable; 3 items)		
Disagreed or no counselling provided	14	(10)
Do not know	38	(27)
Agreed	89	(63)

Table 4. Factors related to the inconsistencies in adherence to care (AC), quality of counseling (CQI) and quality of care transition (QCT) (n=141)

	Support by health care providers ^{†)}		Adherence to care (AC) ^{†)}		Atmosphere during counselling (CQI) ^{††)}		Quality of counselling (QC) ^{††)}		Quality of care transition (QCT) ^{††)}	
	p	Exp(B)	p	Exp(B)	p	Estimate	p	Estimate	p	Estimate
Delivery of counselling ^{#)}										
MD and RN together ^{**)}					.030	-.646	.044	-.771	.031	-1.095
MD and RN alone ^{**)}	.006	17.113								
Respiratory device ^{#)}										
Yes ^{**)}							.027	.664		
Quality of care transition (QCT) ^{#)}										
Positive ^{*)}	.018	12.281								
Increased self-care activities ^{##)}										
Yes ^{*)}			.073	17.291						

#) $p \leq .05$ almost significant; $p \leq .01$ significant †) Binary Logistic Regression ††) Ordinal Regression

) $p \leq .05$ significant; $p \leq .01$ highly significant †) Binary Logistic Regression ††) Ordinal Regression

Exp(B)/Estimate <1: the characteristic of the predictor decreased the risk of the reference category with the dependent variable compared to the reference category with the predictor

Exp(B)/Estimate >1: the characteristic of the predictor increased the risk of the reference category with the dependent variable compared to the reference category with the predictor

*) The reference category with the dependent variable: last (2) = positive value

***) The reference category with the depend

4. DISCUSSION

Only about a third of the participants stated that counseling had been delivered using a patient-centred or multidisciplinary approach. The results confirm the previous theory that hospital discharge is an important step in integrated care.^[3,37,38] When participants reported that counseling was delivered in a multidisciplinary way, they also reported that support from the health care providers was significantly better than otherwise. This supports the theory that multi- and interdisciplinary working in counseling is important^[4,30] to ensure effectiveness.

Only about a third of the participants reported receiving support from the health care providers. The results confirm the theory that experience and feelings shape adherence.^[23] Previous studies have found that support by health care providers is a key mediator for well-being.^[2,17,19,22,23,25,28,29] In health care, work may be based on medical symptoms and a disease-centric approach instead of encouraging the patients in their independent or supported management. It would be unfortunate if patients who need support never receive this from health care professionals.

Thus, counseling has an important role in improving patients' adherence and well-being. As part of counseling it is possible to discuss the causes and consequences related to disease symptoms and strategies for alleviating it. Counselling is an intervention to assist not only in the management of the disease through the use of knowledge, but also to provide social support integrated with self-management.^[2,39] It's de-

livered to COPD-patients that includes self-care training can increase adherence. Patients' experiences of feeling confident and having the ability and skills to manage the temporal progression and changes associated with the disease and its symptoms^[15,26] are central to increasing adherence.

The need for counseling in promoting the value of mastering the behaviour related to self-management is evident. The result supports the earlier finding that COPD-patients' want more information about managing exacerbations and the condition of their lungs.^[40] Successful counseling requires that health care providers have sufficient institutional and professional resources, including time, knowledge, skills and positive attitudes.^[29,41] The inevitable conclusion is that there is a need to assess critically the way all aspects of counseling are currently delivered.

However, nearly all participants in this study were adherent to care. Does this indicate medical obedience or is it an inescapable fact because of the severity of COPD? Obedience, without any chance of patients assessing the relevance of the advice or prescriptions, is not always the best way of reacting to health changes. In addition, this situation devalues the patient and their humanity.

COPD-related distress and negative emotions should be considered in a wider context, not only as a source of anxiety and depression treated by medication. They should be considered specifically in the management of COPD-patient adherence, which often cannot be treated simply by the use

of medication, but requires social interaction. It is necessary to ask whether it is possible to identify such COPD-patients reliably, and whether the expertise is available and attitudes sufficiently developed to allow staff to work towards exploring ways to relieve patients' negative emotions.^[1] This matter is important both for the patient and for the quality of managed health care.

5. LIMITATIONS

First, the patients' enrolment in the study may be biased because of the use of nurses to distribute the survey and it was used self-estimate questionnaire. Nurses are busy and they may have been unable to achieve systematic survey delivery. Analysis of the missing cases could not be undertaken because making a personal data register of participants who did not participate is considered unethical. In Finland all personal data registers are under the supervision of the Office of Data Protection, a part of the Ministry of Justice, to ensure the privacy of citizens. Second, counseling is not exclusively delivered in hospital units but should be implemented according to the varying needs of the patients and the resources and limitations of the hospital. Third, all questionnaires, except CTM-3[®], were slightly modified for use in COPD context. Fourth, data from one tertiary hospital was based on convenience sampling^[42] but was justified by gathered data from respiratory nurses working in the same units. It enables the

comparisons between nurses and participants.

The survey strengths lie in fact that the data were collected using a recognized instrument with a high degree validity and high reliability, instruments are widely used.^[20, 25, 29, 30, 32, 33]

The theoretical background was solidly grounded ensuring construct validity but not tested statistically. The modifications of the instrument were made to make it more understandable for patient with COPD.

6. CONCLUSION

The patient with COPD adhere well to care, but they need support from health care providers. Multidisciplinary team and high quality counseling is crucial, although in practice delivery is not always appropriate for the patient. Counseling should be considered more closely and broadly in the patient care context in hospitals, and those strategies within counseling that enhance adherence should be strengthened and incorporated into standard practice.

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CONFLICTS OF INTEREST DISCLOSURE

The authors declare that there is no conflict of interest.

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