Providing Patient and Caregiver Training  
2010

An electronic literature search for articles published between January 1990 and October 2009 was conducted by using the MEDLINE, CINAHL, and Cochrane Library databases. The update of this clinical practice guideline is the result of reviewing a total of 7 clinical trials and systematic reviews, and 33 articles investigating patient, family, and caregiver training. The following recommendations are made following the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) criteria: (1) It is suggested that RTs take an active role in educating patient, family, and caregivers in the management of their cardiopulmonary disease state. Key words: patient care training; caregiver training; teaching health literacy; cultural competence and patient education; medical outcome. [Respir Care 2010;55(6):765–769. © 2010 Daedalus Enterprises]

PCGT 1.0 DESCRIPTION:

1.1 Patient, family, and caregiver education provides all involved the means of participating in the patient’s healthcare management to the extent feasible, depending on physical condition and awareness. The term family encompasses the person(s) who play a significant role in the patient’s life and may include persons who are not legally related to the patient.1-3

1.2 The training process should occur with every encounter between the healthcare providers and the patient, family, and caregiver.

1.3 The goal of the respiratory therapist (RT) should be to provide patient-centered care and to provide information to and elicit input from the patient and caregiver in a culturally competent manner. The RT’s intention should be to elicit a positive change in the patient and/or caregiver’s behavior through the use of verbal, written, and visual communication in the affective, cognitive, and psychomotor domains, provided with awareness of the patient’s and caregiver’s individual communication and learning needs. Coordinated efforts by RTs and other healthcare providers should provide the patient with an improved understanding of healthcare needs, therapy, proper use and care of all medical equipment/supplies, coordinated use of multiple pieces of equipment as applicable, troubleshooting, and the importance of adherence to medical regimen and candid communication with caregivers. Self-management and self-advocacy skills should be emphasized as appropriate. This should enable the patient to better manage the disease through cooperation with the caregiver and RT in an active partnership.3,4 All members of the team, including the patient, family, and caregivers, need to be aware of these goals as an aspect of the patient’s total care.

1.4 An additional goal of the RT’s contribution to education and training is to improve patient care and to provide the patient, family, and caregiver with the means to improve utilization of the healthcare system.5,6

1.5 Information and teaching methods should be in compliance with federal and state legislation and organizational accreditation requirements regarding language, communication needs, and cultural values. Healthcare providers need to know the laws concerning patient rights and provider responsibilities related to language, communication needs, and cultural accommodations.

1.6 Finally, RTs and other healthcare provider’s involved with patient, family, and caregiver training need to know best practices and teaching methods, focusing on patient-centered care.7-9

PCGT 2.0 PROCEDURE

RTs initiate a process with the patient, family, or caregiver to acquire knowledge and skills for the prevention and treatment of a cardiopulmonary medical condition.

PCGT 3.0 SETTINGS

Patient, family, and caregiver training settings include, but are not limited to:

3.1 Acute care hospital
3.1.1 Patient’s room  
3.1.2 Designated teaching area or learning center  
3.1.3 Pulmonary rehabilitation department  
3.2 Out-patient rehabilitation center  
3.3 Patient’s home  
3.4 Physician’s office or clinic  
3.5 Extended care or skilled nursing facility  
3.6 Patient support group meetings  
3.7 Community education seminars  
3.8 Durable medical equipment (DME) office

PCGT 4.0 INDICATIONS

The presence of a patient population with the need to
4.1 increase knowledge and understanding of health 
status, disease pathophysiology, and therapy  
4.2 improve skills necessary for safe and effective 
healthcare (ie, inability to perform needed therapy)  
4.3 foster a positive attitude, stronger motivation, and 
increase adherence to therapeutic modalities  
4.4 know the answers to “Ask Me 3”: What is my 
main problem? What do I need to do? Why is it im-
portant for me to do this?

PCGT 5.0 CONTRAINDICATIONS

There are no contraindications to patient and caregiver 
training when a need exists.

PCGT 6.0 HAZARDS/COMPLICATIONS

6.1 Omission of essential steps in care, inconsistency 
in information presented, or failure to validate the 
learning process can lead to untoward results.  
6.2 Lack of cultural competence, lack of materials in 
Plain Language, lack of information appropriate to the 
language needs of the patient and/or caregiver, includ-
ing languages other than English and American sign 
language will also result in less than desirable out-
comes.  
6.3 Lack of trust by the patient, family or care pro-
vider of the medical team, institution or individual 
lector.

PCGT 7.0 LIMITATIONS OF METHOD

7.1 Patient limitations:
7.1.1 Lack of motivation or interest in acquiring 
knowledge or skills  
7.1.2 Impairment (eg, in hearing or vision, poor 
dexterity, decreased energy, strength, learning de-
fects or stamina, age-specific, pain, or medication 
adverse effects)

7.1.3 Inability to comprehend or lack of aware-
ness due to factors such as anxiety, depression, 
hypoxemia, substance abuse. This may include 
education.
7.1.4 Negative response to past educational ex-
periences or encounters
7.1.5 Lack of health literacy, despite level of ed-
ucation completed. This may include func-
tional illiteracy in dealing with the healthcare pro-
cess.
7.1.6 A mindset that leads to misapplication, mis-
interpretation, or rejection of instruction as irre-
levant
7.1.7 Language that is different than that of the 
healthcare provider
7.1.8 Conflict of religious beliefs and/or cultural 
practices with material presented or the manner 
in which it is presented
7.2 Healthcare provider limitations:
7.2.1 Lack of positive attitude or adaptability  
7.2.2 Limited understanding of knowledge or skill 
to be taught  
7.2.3 Inadequate assessment of patient’s need or 
readiness to learn and inability to individualize the 
instructional approach to the patient, includ-
ing age-specific needs
7.2.4 Multiple patient needs and training goals to 
be met in the allotted time
7.2.5 Inappropriate or inadequate communication 
skills (eg, unnecessary use of medical terminol-
gy, lack of listening skills); lack of documenta-
tion or discussion with other team members; in-
consistency in information presented
7.2.6 Inadequate knowledge of cultural or reli-
gious practice that may affect educational pro-
cess, communication, or adherence to the plan of 
care
7.2.7 Inadequate teaching skills of the healthcare 
provider/RT conducting the training
7.3 System limitations:
7.3.1 Hospital stay too brief  
7.3.2 Absence of interdisciplinary cooperation and communication
7.3.3 Inconsistency in information provided
7.3.4 Failure to coordinate the assistance of family or community based interpreters
7.3.5 Education and training started too late in the discharge planning process
7.4 Psychosocial limitations
7.4.1 Absence of support system
7.4.2 Reimbursement issues
7.5 Environmental limitations:
7.5.1 Inadequate lighting, poor temperature control, uncomfortable seating, inadequate space for demonstrations.12,16
7.5.2 Interruptions, distractions, and noise that interrupt the learning environment.12,16
7.6 Failure to use trained interpreters. Failure to provide translated vital materials for language groups meeting the numerical threshold.27 Poorly chosen resources, including inappropriate reading level and vocabulary.4,12,27

PCGT 8.0 ASSESSMENT OF NEED

8.1 Determine knowledge base.6,11,12,26
8.1.1 Interview patient/caregiver(s) regarding past experience with topic being taught.11,12,18 Ascertain their beliefs about cause of illness, its meaning in their lives, how they would traditionally treat it. A published or self-generated guide may be used.2
8.1.2 Discuss what patient/caregiver(s) perceives as knowledge relevant to his care. A written test may be used to determine knowledge base.19,20,25,26,29
8.2 Observe patient’s/caregiver’s performance of therapy and determine whether skills are adequate for self-care.32
8.3 Determine whether patient’s/caregiver’s attitude and outlook appear to be conducive to participation in his or her healthcare.20,33-36
8.3.1 Assess patient’s/caregiver’s motivation or emotional readiness to learn and change behavior as it relates to his or her healthcare. Be sufficiently knowledgeable and culturally aware to explore with referring physician the need to amend a treatment plan to be bi-cultural, in situations where performance and adherence would improve.3,7,9,12,14,15
8.4 Determine the most appropriate method, location, and time for training.
8.5 The healthcare provider/RT trainer should ask and document if the patient and/or family is using alternative therapies in addition to Western prescribed plan. The response to such inquiries also needs to be documented and conveyed to other team members.
8.6 The patient, family and/or caregiver also needs to be asked if other family or community members are involved in decisions regarding adherence. Response should be documented and conveyed to other team members.

PCGT 9.0 ASSESSMENT OF OUTCOME

9.1 Assess knowledge gained and skills mastered.
9.1.1 Obtain feedback about specific aspects of information presented and note questions asked.14,19,27
9.2 The patient should return demonstration without assistance.3,14,16,37
9.2.1 Observe patient’s/caregiver’s ability to adapt new skill to novel or unfamiliar situations.6,15,38,39
9.2.2 Determine skill adaptability in home environment via telephone calls and/or home visits. A Home Environmental Assessment prior to discharge, to ensure functionality of electrical, heat, air conditioning, and other physical attributes to the patient’s home is essential.2,15,28
9.3 Reassess patient outlook, attitude, and lifestyle changes.
9.3.1 Determine through discussion with patient and family whether patient feels more in control of condition and care.12,14,16,39
9.3.2 Consider the use of quality-of-life inventories, such as the COPD Self-Efficacy Scale,32 the Chronic Respiratory Disease Questionnaire,29 the 36-item Medical Outcomes Study Short-Form questionnaire (SF-36),29,30 the Sickness Impact Profile,31 Center for Epidemiologic Studies Depression Scale (CES-D), the Pulmonary-Specific Quality of Life for COPD Scale, Coping Skills Training,36 and the Pediatric Asthma Caretaker Quality of Life Score.31
9.3.3 If desired outcomes are not achieved within the expected time frame, or if additional concerns are identified, the healthcare provider is responsible for notifying the ordering physician.
9.3.4 Identify possible causes of failure to achieve desired outcomes, including failure to address cultural, language, or communication needs.

PCGT 10.0 RESOURCES

10.1 Need to know how to access trained interpreters, via telephone or in-person
10.2 Training materials
10.2.1 Written materials
10.2.1.1 Readability and comprehension should be at approximately the 5th to 6th grade level. (This may be assessed with the Simple Measure of Gobbledy-Gook (SMOG) scale or the Rapid Estimate of Adult Literacy in Medicine (REALM) scale.26,27 A glossary may be helpful.
10.2.1.2 Large, dark print on white page is preferable.5,21,23
10.2.1.3 Material should be easy to handle, with space for instructions and/or notes.14
10.2.1.4 Simple terms and short sentences encourage use of material.14
10.2.1.5 Verbal and written materials, as well as teaching approaches, should adhere to Plain Language principles.32,36
10.2.1.6 Illustrations may aid comprehension.9,23,33
10.2.2 Materials in alternative formats (eg, audio, visual) may be helpful. Translated materials per the United States Department of Health and Human Services 4-prong identification32 (need and organizational capability).2,7,32
10.2.3 Demonstration models or samples may be useful for hands-on training and practice.
10.2.4 Education should be initiated as early as possible, to ensure training is completed by discharge in an appropriate environment.5,9,12,29
10.2.5 For long-term care, knowledge and skills should be reviewed at regular intervals, for patient and main caregiver and for new caregivers who may have started subsequent to original training.
10.2.6 Personnel
10.2.6.1 All healthcare providers should have skills commensurate with the level of care that they provide to the patient.2,3,11,12,14,15,18,30,33,34
10.2.6.2 Professional interpreter as needed (use of friends, family members, and children should be actively avoided).36

PCGT 11.0 MONITORING

11.1 Monitoring the patient training process should include awareness of patient’s verbal and nonverbal responses to what is being taught.
11.2 The assessment of readiness for self-care may be made by working with the discharge planner.
11.3 Patient’s instruction and the outcome should be documented and made available to all persons providing patient care.
11.4 Track adherence following education, and training.36,37
11.5 Assess whether possible adherence issues involve cultural or communication issues, and bring these concerns to referring physician and other team members.

PCGT 12.0 FREQUENCY

12.1 With each patient encounter, or as appropriate by type of monitoring question.
12.2 Schedule patient or group appointments as needed.
12.3 Closed-circuit hospital video presentations may be presented several times on a given day and repeated as indicated.

PCGT 13.0 INFECTION CONTROL

13.1 Implement standard/universal precautions.32
13.2 Observe all infection-control guidelines posted for patient.
13.3 Communicate any and all infection-control concerns or risks to all persons providing patient care.33

PCGT 14.0 RECOMMENDATIONS

The following recommendations are made following the Grading of Recommendations Assessment, Development, and Evaluation (GRADE)38,39 criteria:

14.1 Level 1. It is suggested that RTs take an active role in educating patient, family, and caregivers in the management of their cardiopulmonary disease state. (2C)

PCGT 15.0 IDENTIFYING INFORMATION AND AVAILABILITY

15.1 Adaptation
Original Publication: Respir Care 1996;41(7):658-663.
15.2 Guideline developer
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REFERENCES