

The LUEBECK Approach in Palliative Medicine

Andreas S. Lübke*¹

Frank Gieseler²

¹Department of Internal Medicine, Karl-Hansen-Klinik, Antoniusstraße 19, 33175 Bad Lippspringe, Germany

²Department of Internal Medicine, Clinic for Haematology and Oncology, Palliative Care and Ethics in Oncology, University Hospital Schleswig-Holstein, Campus Luebeck, Germany

Abstract

The LUEBECK APPROACH is a knowledge-generating didactic tool to guide the medical professional through the course of the support of a palliative-care patient with the purpose to transform unique and individual conditions into clinical practice. Therefore, by the APPROACH, symptom control will be optimized, and physical as well as mental and psychological well-being can be enhanced. The APPROACH also raises the awareness, that an individual and dynamic response should follow the patient's changing condition. With the seven step APPROACH, that includes elements of "narrative medicine", it is possible to create more clarity of the situation and transparency of the measures taken. Experiencing this may help the patient to build trust and faith in the glare of sickness and death. The LUEBECK APPROACH, has proven to serve as a useful checklist for a structured and comprehensive assessment as well as for a treatment plan. By learning from one patient, the next patient will benefit, the care team will grow and the service delivered can be assured.

Keywords

Palliative care, guideline, prognosis, life time expectancy, strategy, knowledge-generating patient care model, checklist, model.

Introduction

Palliative medicine is provided for patients with far-advanced, life-shortening chronic disease. It is important for any professional to develop a structured approach for the best possible care of patients who need palliative care. Within this approach, dynamic adaptations to changing physical and emotional conditions may prove to be necessary. At the end of a treatment period, ideally, knowledge gained from one patient will be shared within the team and such knowledge will be used as a basis for the next patient's treatment. Patients suffer from symptoms, functional deficits, psychosocial problems and they may experience spiritual needs. During this phase in life many problems and challenges typically coincide and escalate the situation.

One example of the complexity is the concept of "total pain", meaning that several individual factors, such as loneliness, existential questions and the loss of functional capacity may interact and amplify how the patient experiences pain. A multidisciplinary approach has proven to be effective in treating pain in a palliative medicine setting, far more so than administering increasing amounts of analgesics. For this reason, as many pieces of background information as possible should be collected from one patient before any treatment will be initiated. It is, therefore,

Article Information

Article Type: Conceptual Article

Article Number: JHSD-145

Received Date: 27 January, 2022

Accepted Date: 28 February, 2022

Published Date: 07 March, 2022

*Corresponding author: Andreas S. Lübke, Palliative Care Unit, Karl-Hansen-Klinik, Antoniusstraße 19, 33175 Bad Lippspringe, Germany. Tel: +491735350159; Email: a.luebbe@medizinisches-zentrum.de

Citation: Lübke AS, Gieseler F (2022) The LUEBECK Approach in Palliative Medicine. J Health Sci Dev Vol: 5, Issue: 1 (17-21).

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important for any professional in palliative care, be it a doctor, a nurse, a social worker, a physiotherapist, a nutrition specialist or a spiritual counselor, to work together and to share as much as possible from the collected background information (i.e. family status, professional career, attitudes, cultural belonging, religious belief, intellectual capacity, verbal and mimical expression) to be able to take care of the patient in the best possible way.

The LUEBECK APPROACH has been developed during the past decade of teaching and experiences in the treating of palliative care patients in three different settings – two palliative care units at the University of Hamburg and Lübeck as well as one in a community-based hospital in Bad Lippspringe. Although it is a theoretical framework, the APPROACH is focused on practical aspects with the aim to improve the cooperation between different players and to ease the practical care of our patients. We are convinced that it can help by setting up a standard method in patient assessment and treatment. Our structured APPROACH helps to avoid accidentally not to omit key steps in the assessment and evaluation of the treatment success, and it guides professionals through the process.

Checklists have proven to be helpful in various settings, such as the SPIKES-model for breaking bad news or the NURSE model for coping with patient's emotions [1,2]. Other models in palliative medicine, such as the CARE-model for the response against rage and verbal attacks, or symptom check lists or quality of life questionnaires, serve as a guideline with the aim not to forget crucial items in a certain context [3-6]. Other models focus on service delivery or help with documentation [7-8].

To our knowledge, there is no published structured approach available in palliative medicine for professionals that helps with the initial patient encounter as well as serves as a guide through the treatment plan all the way to the next patient. We believe, that the proposed form of standardization can be helpful, for it includes crucial elements that are necessary to consider in palliative care and because it incorporates measures of quality control.

Concept

Like other acronyms each letter of the LUEBECK APPROACH stands for a concept, an idea or a task the user can memorize and retrieve when necessary. The flow of letters follows the initial approach we take when visiting a patient at home, on a hospital ward or in an ambulatory setting. It implies that we do not know the patient yet and that we want to do all we can to help. The typical clinical goals in palliative medicine are symptom alleviation, the improvement of physical and mental strength, the optimization of psychosocial needs as well as the consideration of spiritual needs. The basis for all this is the best possible assessment of the patient's character and attitude, his knowledge to his status and his biography. In addition, his relation to the family, relatives, friends and colleagues plays a role in our assessment and management. We strongly believe that optimal palliative care is only possible with an in-depth knowledge and feeling for the patients need. Here the

principles of "narrative medicine" come into play, by which the patient essentially tells a story, step by step, that forms the basis for our clinical practice, as we go along. By telling the story (and by our efforts to let the patient tell us his/her story chapter by chapter), we are put into the position to better donate our clinical experience, to better give the patient company, and we better form a sturdy affiliation within our clearings. One helpful way to come close to these goals we think is an in-depth and structured approach together with the establishment of a personal relationship with the patient. Personal means not to be too far away from the patient's emotions (we prefer to call it "professional closeness") in order to be part of the story, yet we need to protect ourselves from being emotionally too much involved so that good decisions would be prevented (we need a certain amount of "professional distance"). However, without a certain degree of "professional closeness" and without some kind of personal relationship good palliative care will not be possible. The human being at the end of life is in need of another human being who listens and feels and understands and helps. The LUEBECK APPROACH is a helpful tool in getting to that point.

L - Learning about the patient:

Before we get into a personal encounter with the patient for end of life care, we must learn everything we can from the available files, charts and documents. Perhaps we have to call treating physicians and other health care players to gain a better feeling for the disease and its dynamics as well as for any other possible treatment options. In an age of thriving molecular biology-based treatment options ("precision medicine") all too often possible therapies have not been considered before a patient comes under our umbrella so that treatment options against the disease are still left open. If this is so, we enquire about them and keep them in mind before we meet the patient. We want to get a feeling for the rapidity of the progress of the disease and the deterioration of the patient; meaning we look into the past. In other words, we want to know the nature of the disease. Does the patient's cancer typically spread quickly or is the natural course rather slowly? How was it in our patient? How has the treatment been tolerated? What are the other diagnoses and what impact do they have on the life-threatening disease? What other pieces of information can we acquire that help us understand the medical background? All of this enables us to understand the situation and to set up a prognosis. Therefore, the second step of our approach touches the future.

U - Understand:

We want to establish a prognosis for our patient, i.e. arrive at a decision as to what the life-time expectancy most probably will be. There are several ways to arrive at a fair estimate [9-11]. The age of the patient and the nature of the disease and its treatment history are paramount, but accompanying diseases are crucial as well (see above). What are they, how long does the patient suffer from them, how have they been treated. How relevant are they, would they diminish the life span? The nutritional status is important. Has the patient lost weight, if so, how much in in what

time? Can she/he eat and drink now? If so, how much and with what effort? What are her/his physical reserves? How strong is she/he, can she/he leave the bed (how many of the 24 hours will be spent in bed?), what is the result of a six-minute walking test, or is it not even possible to perform that test? What is the hand grip strength, does heart rate variability show a low parasympathetic (vagal) status? Has a cachexia-syndrome already been diagnosed, do other laboratory values rather point to a short life expectancy, such as high LDH and CRP and low albumin and sodium? With those and other parameters it is possible to reach a realistic estimate of around 80 to 90 percent, whether our patients life will last for only a few days, a few weeks, a few months or perhaps a year. It is our firm belief, that the assessment of the individual prognosis is mandatory for the good practice of palliative medicine, because diagnostic procedures and therapeutic interventions depend on it.

E – Examine the attitude of the patient:

After these preparations contact with the patient will be initiated. We favor a more open approach according to the principles of “narrative medicine”, an attempt that establishes a kind of “professional closeness” that we mentioned above and that can perhaps best be described as an encounter from one human being to another.

The principles of “narrative medicine” go back all the way to 1910, in which the Carnegie Foundation for the Advancement of Teaching has created the Flexner Report, which set out to redefine medical educational practices [12]. The principles of “narrative medicine” have been reintroduced to the scientific community by Remen and Charon in the 1990s [13,14]. One way how the professional might introduce her/himself to the patient is by saying something like: *“I will be your doctor, and need I to know a great deal about your body and about your life. Tell me, what should I know about your situation?”* By doing so, and by using similar techniques of communication, the relation between the professional and the patient can become more personal. Together with the many observations (made by the professional) while responding to the initial offer (to the patient to talk about oneself) multiple pieces of information can be absorbed and interpreted. What is the initial response to the offer? Does the focus lie on the disease, or does it lie rather on the grandchildren’s future? How does the patient respond? Is he/she too weak to talk or unwilling, or rather the opposite? What are his/her movements, mimic, gestures? What is the content and how many emotions is the patient willing to share? During these moments the professional gains a deeper insight into the personality of the patient and her/his coping. The patient begins to tell a story, and the professional listens. What is the burden of suffering, is the patient willing to let us relieve it or does the patient even have an own treatment concept? Taken together, during this step and over the following encounters with the patient, we establish a (more or less intimate, yet professional) relationship that forms the basis for an individual closeness or distance.

We continue to write a story about the history and bibliography of the patient. That story grows chapter by

chapter, but it will never be complete. We become aware of what the patient knows about his/her (disease) situation, what he/she has been told (as to further treatment options and the remaining life span) and what the patient makes out of the information presented. It is our obligation to find out if the patient has an understanding of the meaning and the impact of the data and facts that have been presented to her/him. We also use our patient encounters for the assessment and physical examination of the patient symptoms and findings.

B – Bring our knowledge to the patient:

After evaluation of the theoretical background as well as the practical encounter with the patient we bring that knowledge together with all we have learnt back to the patient. Now is the time to act and to find solutions and to come up with concrete ways and means to relieve symptoms and to improve findings. Did the patient understand what we have said? Does the attitude of the patient coincide with our assessment? Are his/her wishes realistic and does our approach go hand in hand with what the patient expects from us? Now is the time for us to offer our concrete support regarding symptom control and psycho-social and spiritual needs. We may want to improve body functions, such as speaking, swallowing, muscle strength and joint mobility and we use all the knowledge about the patient together with the skills and the principles we have acquired, to assure that the patient is in our good hands.

At the end, we develop a short-, mid-, and long-term treatment plan that you might call a strategy. Within this strategy, we favor the concept of “guided-decision-making” rather than “shared-decision-making”, because to our mind the term “guided” better represents the role of the professional. Professionals guide the patient through the time, rather than “share” something with him. In fact, we feel it hard to imagine sharing with the patient life goals and quality of life aspects or certain interests. “Guided-decision-making” also does not mean that the patient’s wishes are neglected, quite the opposite. The professional rather decides in the light of the story the patient has told him so far what could be offered and the patient responds to that offer.

The last three letters of the LUEBECK APPROACH focus on quality control items and the dynamic adaptations in response to the patients’ symptoms, findings, attitudes and wishes.

E - Evaluate the treatment plan:

As we have all learned at school, there is no medical or therapeutic management without re-evaluation. We want to know, if our diagnostic measures have led to a treatment decision, if our treatment decisions have alleviated the symptoms, if our plan will be followed by the patient (and his family/friends), and if our assessment has been correct. In other words, we want to evaluate our success and we want to know if something went wrong. Have we reached our treatment aim? E. g., could we reduce the bone pain of our patient at night? Did the physiotherapist improve the mobility? Perhaps drugs have to be taken away, added, changed or rotated, decisions may have to be revised,

postponed or given up. Perhaps complications now change our plan and unknown factors cause new problems. We evaluate our treatment as often as necessary, at least once a day, sometimes several times per day, occasionally every few days. Often times measures taken need a few days to set in.

C – Check the overall plan in regular intervals:

As for many other strategic endeavors inside and out of medicine it is a good advice to step back at regular intervals in order to take a fresh look at the whole enterprise, here at the treatment plan of a patient on a palliative care unit or in an ambulatory setting. Can the original goals be reached? Does the family/friends go along? Are the wanted effects worth the unwanted side effects? Does the patient really understand what we are doing, do we understand what the patient still wants? In other words, are we on the right track? Do we have all the resources we need to accomplish our goals? We do this twice a week, on Mondays and on Thursdays.

K – Knowledge as a recap and prompt for the next patient:

Whatever we have learned from our patient, it does form an even firmer ground for the treatment of the next one. After our patient has left us (i.e. has been dismissed to hospice care/nursing home or to his family, or has died), we should take the time to ask ourselves what went well and what went wrong. What would we do differently, if the next patient comes to us with similar framework conditions (symptoms, findings, expectations and such)? We think it is important to reevaluate the stay of the patient as a whole. Special rewards, needs or burdens of the caretakers might also be worth recapitulating with the objective to generate knowledge for the care of the next patient. Although we did not evaluate, we believe that especially by this element of the LUEBECK APPROACH, typical burn-out symptoms from the personnel can be prevented, be reduced or better be coped with. Burn-out has been observed especially in teams that face emotional burden and in which the members have few opportunities to cope. Besides, supervision, regular round-ups or recaps constitute as a firm part in our routine work. We recapitulate the patient around one week after he/she has left us.

Discussion and Conclusion

Over the course of the last two decades palliative medicine has developed rapidly and has found its way into the curriculum of medical schools. In many countries physicians can specialize in the field, research efforts are being expanded constantly and guidelines set standards in the care of patients. Palliative medicine is the medicine at the end of life. Therefore, not only the physical problems contribute to the suffering of the patient, but also the psychological and spiritual aspects and the existential threat that needs to be taken care of. For these reasons the role of the doctor (and that of any other professional who deals with palliative care patients) goes far beyond diagnosing or treating a disease. Over the course of the past two decades it has become clear that palliative medicine

is a multiprofessional, interdisciplinary approach with the primary objective to relieve suffering and to provide a smooth end of life in dignity [15,16]. Often times there is not much time left, and we professionals have to get to know the patient as well as possible and as soon as possible, in order to be able to relieve the suffering and to answer existential questions.

During our teaching at various university hospitals we have taught our students basic and advanced principles of symptom control and we have done our best to make physicians understand how important it is to bring together specialists from other fields for best possible care. We have set up our curriculum and emphasized ethical principles. Yet, knowledge alone does not make a good palliative care professional. What we do with all the information, is one of the crucial questions that we should ask before we let ourselves become part of the patient's history. That is why we have developed the LUEBECK APPROACH.

We have used it over many years, and we feel now the time has come to introduce the APPROACH to a wider audience. While there are numerous acronyms in medicine that serve as checklists, reminders or guidelines, the LUEBECK APPROACH focusses on a structured way of how to guide both, the student as well as the professional through the treatment path of a patient with advanced and life-shortening disease. Most checklists or acronyms focus on special tasks or fragments, but the LUEBECK APPROACH represents a comprehensive guide through the course of the patient's treatment plan in palliative medicine.

We believe that the original approach by Flexner is still valid today. He stated that "*the practitioner deals with two categories. Chemistry, physics, biology enable him to apprehend one set, he needs a different apperceptive and appreciative apparatus to deal with the other more subtle elements*"[11]. Specific preparation in this direction is much more difficult and is being taught rarely. We think however, this approach can be crucial in palliative medicine. Therefore, this concept should be integrated in our LUEBECK APPROACH. Because suffering is such an individual perception (that is expressed in a very individual fashion), we can succeed in our effort to relieve it only when we come as close as possible to the nature of a patient's personality. Otherwise, it is difficult to understand the nature and the intensity of that suffering.

"Narrative medicine" is one way to get close to the uniqueness of a patient, by letting him or her tell us his/her story chapter by chapter. During our encounter with the patient we do what we always do; we see and hear, we smell and listen, we ask open questions and we respond when appropriate. The more we know the more we understand and the more we understand the better we are in using the right tool against the many reasons for suffering, but without a certain amount of "professional closeness" and trust symptom control will fail. Symptoms remain subjective impressions and the approach for optimal symptom control therefore remains unique and subjective. The more I know about a patient, and the closer the relationship is and the more trust waves through the mutual relationship between the professional and the patient, the more successful

symptom control will be.

During the time we care for the patient, which may last for days, for weeks or for months, we may repeat certain elements of the LUEBECK APPROACH. Checking our efforts and fine tuning our medication (e.g.) is mandatory over the course of our care. And it is one of the fundamental medical principles to respond to an intervention if that intervention has not fulfilled its goal. It should be basic medical practice to retain whatever has worked in one patient to use that experience in the next. For thousands of years' medical practitioners have used the knowledge, the experience and the wisdom of their teachers and peers to practice, before they themselves become experienced doctors and pass on their knowledge and skills to the following generation. We call this empiric medicine. In the 20th century more and more data have been collected and evidence-based medicine came into play and threatens good old-school empiric medicine. However, in palliative medicine, although much progress has been made, still comparatively few data are being collected and very little evidence-based medicine can be used. Patients are often old and suffer from several diagnoses. Observation times are rather short. This and other factors prevent multicenter prospective randomized clinical trials. In other words, empiry and the personal approach remain of fundamental importance in palliative medicine.

While the typical PDCA (plan, do, check, act) – cycle is being used in many companies that produce and sell products or provide services, the PDCA-cycle is not too well-known in medicine. Its original intention is to develop a company further, to make better products or to facilitate processes. We believe that the PDCA-cycle could be used in palliative medicine, too - and in a very concrete way. Whatever has proven to be successful in the treatment of one patient should be important for the next one, too. So, the LUEBECK APPROACH also focusses on other, future patients. Although much of what builds up our memory and contributes to our professional experience may be a subconscious process, a structured approach to recap what went well in one patient or what has gone wrong will help future patients. Taking this also into consideration will let the whole team grow and help to become better and to prevent burn-out symptoms. Taken together, we believe, that the LUEBECK APPROACH is a useful tool for any student or professional who engages in the wide field of palliative medicine.

Acknowledgement

Thomas Kress, a clinical psychologist of the MZG-Westfalen, helped with the English wording of this paper.

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